Body on Alert!

Living with Rheumatoid Arthritis:

Non-geriatric Individuals in the Netherlands
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Annex 65
These are hands of Marian. She is 40 years old and suffers from rheumatoid arthritis since she turned 16. After having many bone replacement surgeries she calls herself as ‘bionic women’. Despite her disturbed health she manages to keep her spirit high up. This photo and her name are printed with her permission. You may trace her story throughout this research as the Respondent (40).
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Nino Gurgenidze

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Summary

There are many forms of arthritis. Rheumatoid arthritis (RA) is one of the most disabling types of arthritis. The prevalence of RA in the Netherlands varies between 0.3% and 1% among the total population. There are over 150,000 patients with RA registered in the Netherlands. The prevalence of RA higher in women than in men and also increases with age in both sexes but it most commonly starts between the ages of 30 and 50 (Central Bureau of the Statistics, the Netherlands 2007). The condition can have a very disruptive effect on the lives of sufferers. One in three sufferers believe that the condition controls their life. The disease process, in general affects all aspects of individual’s life including physical, psychological and social well-being. In the existing literature the predominant approach to study RA was the biomedical model, which was focused on the physical process, such as pathology, biochemistry and physiology of the chronic illness. The major limitation of this approach was that it did not show what kind of process takes place when person undergoes disruption in his/her health.

This research study used anthropological methodology and theory to explore how non-elderly people in the Netherlands affected with RA experience and interpret chronic illness and associated chronic pain. In particular, the research studied how RA affects individuals’ psychological and social well-being. This research shows how the interpretations of the emic perspectives of RA affected individuals match the theory of the body and self identity. The study is exploratory and is focused on the micro level. Ten people affected with RA between the ages 37-52 participated in this qualitative study.

The study showed that while the onset and progress of RA imposes severe physical and emotional burden on the sufferers, the respondents strictly divide and distance their ‘selves’ from the challenges imposed by RA, thereby they succeed in experiencing themselves as ‘normal’. Based on these findings, the important conclusion of this study therefore is that RA does not seem to deeply affect the psychological well-being of the respondents. The study also found that the process of onset and development of RA brings disruption in life and negatively affects the social well-being of the respondents of this study.
1. Introduction

1.1 Statement of the Problem

Rheumatoid arthritis (RA) is a chronic disease affecting one percent of the adult population. People affected with rheumatoid arthritis are confronted with multiple consequences of their disease, including increasing physical disability, chronic pain, difficulties in performing activities of daily living, and growing dependence upon other people. There is no definite cure for rheumatoid arthritis. Therapy is mainly pharmacological, aimed at alleviating symptoms and preventing damage to the joints. Individual patients differ concerning the impact of the disease and its consequences as well as their ability to successfully adjust to them. Follow-up studies among RA patients showed that after 10-20 years of follow-up about 20% of the patients had no or minor disabilities, most of the patients were moderately disabled, and about 10% of the patients suffered from severe disablement (Jacoby et al. 2003). RA is an important health problem which is addressed with little success despite endless endeavors to find key to its full treatment. Affected people have to live with this condition and thus have to learn how to live with it and manage it. Hence, the main problem is that there is a high number of chronic patients who are at a constant state of pain and fatigue and require more systematic involvement from medical and non-medical expertise.

Moreover, suffering from this chronic disease does not only mean deterioration of physical functioning but also deterioration of social and psychological functioning. When living with RA the patient’s social roles, capacity to work, independence, self-concept, mood and psychological well-being are usually affected as well (Krol et al. 1993; Doeglas 2000). Therefore, the second problem is that besides physical hardship, social and psycho-emotional aspects of well-being are highly concerned.

In general RA occurs in people at different ages. It can occur in individuals as early as in teenage and even before. It can progress slowly or abruptly. As already mentioned RA might cause limited functioning or lead to physical disability. In an advanced age for many people it is considered normal to live with physical impairment. There is a certain predictability associated with the occurrence of illness and physical limitation is considered as normal part of aging. But young people who are affected with RA might also suffer from the visible and non-visible consequences of this chronic disease. It invariably affects their muscular-skeletal system and its functioning. Because of the age difference when RA is diagnosed in individuals, it is proposed to think that its occurrence and flow with related consequences differ in geriatric and non-geriatric patients.
Interest of this particular research will be focused on non-geriatric sufferers with RA. The reason for opting for this category is that to study the problems listed above will give us insight what kind of transformation a person will undergo whose medical condition is not attributed to his/her advanced age. Young people affected with RA may have limitations in physical functioning but in contrary to the advanced age patients, this is not attributed to the process of so called “wear and tear”.

The study of chronic pain is another particular area of this research. Anthropology also looks into how pain is experienced in everyday life and the embodiment of cultural categories of distress. Kleinman (1999) suggests that it also studies how the bodily experience itself is influenced by meanings, relationships, and institutions. As Kleinman (1999) defines illness is what body dysfunction means to the person suffering.

To understand chronic pain from RA affected individuals’ point of view will be one more step to further explore the field of chronicity. Consequently, from the findings of this research, patients may benefit from learning about self-management interventions aimed at enhancing their self-esteem and ability to manage their disease thus improve their physical and psychological functioning (Barlow et al. 2002; Mulligan and Newman 2003). Psychological strategies to change a patient’s perceptions of stress caused by disease and pain may be appropriate in this context.

I consider that daily experience of pain and fatigue among individuals with RA is an everyday remainder of an onset of chronic disease at an early age. Also, the fact that they have to live with this condition during many years, sets its demands to rethink life plans and adjust to the new life circumstances.

Rheumatoid arthritis is one of the most disabling types of arthritis. Rheumatoid arthritis is an autoimmune disorder, a condition in which the body attacks itself. It can occur at any age. More than 60 percent of people with rheumatoid arthritis are women. It is a disabling and painful inflammatory condition, which can lead to substantial loss of mobility due to pain and joint destruction. It most often affects the wrists, ankles, knees, and toes. Rheumatoid arthritis causes the joints to become inflamed, stiff, and painful to move. If not treated, joints may become deformed and loss of movement may occur.

The prevalence of rheumatoid arthritis is relatively constant in many populations, at 0.5-1.0%. There is some evidence that it may have been brought from North America to Europe during the 18th century. Its arrival in rural parts of the developing world is still more recent. The incidence and prevalence of RA appear to have fallen in Europe, North America and Japan in the last 50 years. During this time the peak age of onset has risen. Risk factors for the development of RA include genetic factors, an adverse pregnancy outcome, smoking, obesity and recent infections (Symmons 2002).
Several studies indicate that host factors (e.g., age and sex), environmental factors (e.g., Epstein-Barr virus infection), and genetic factors (e.g., genes in the human lymphocyte antigen region) may all play a role in the etiology and pathogenesis of rheumatoid arthritis. Clinicians and researchers have frequently noted the familial clustering of rheumatoid arthritis, which suggests genetic and environmental determinants (Kwoh 1996). Rheumatoid arthritis is actually a family of related diseases, not a single entity. A family history of rheumatoid arthritis increases a person’s risk of getting this disease, but most persons with this disease are the only ones in the family with it. The problems are primarily a consequence of persistent inflammation.

Among the adults it affects, the female to male ratio is three to one. RA incidence also varies by age within each sex. Among women, disease occurrence increases from the age of menarche and peaks around menopause; RA is rare in men under age 45. These trends have prompted numerous studies into the role of hormones in the development of RA. However, sex differences in specific risk factors, disease expression, and response to treatment have remains largely unexplored (Jawaheer 2006).

Women with rheumatoid arthritis are less likely to experience remission than men. Gender is a significant factor in disease progression with one third of the women being in remission at two years compared to nearly half of the men (Annals of the Rheumatic Diseases 2006).

1.2 Rheumatoid arthritis in non-geriatric patients in the Netherlands

The incidence of rheumatoid arthritis in populations of northern European origin is 20–300 per 100 000 per year and that of juvenile rheumatoid arthritis is 20–50 per 100000 per year. Currently registered RA patients in the Netherlands amount to 149, 983 in total (Central Bureau of the Statistics, the Netherlands 2007). The prevalence of rheumatoid arthritis in most industrialized countries varies between 0.3% and 1%; in developing countries it lies at the lower end of this range (Woolf 2003).

In the existing literature the predominant approach to study RA was the biomedical model, which focuses on the physical process, such as pathology, biochemistry and physiology of the chronic illness. The disease process in general covers all aspects of individual’s life including physical, psychological and social well-being. The major limitation of this approach is that it doesn’t take into account psychological and social factors, hence psycho-social aspects are not covered widely enough in order to show what kind of process takes place when person undergoes disruption in his/her health. In very general terms, health disorders of the musculoskeletal system attributed to different kinds of arthritis is usually considered something which is associated with advanced age in both sexes.
Although, as mentioned many types of arthritis can be triggered at a very early age. It can occur during the juvenile period, puberty or during any other change related process in human life. Those processes can be regarded as significant life stages such as getting education, creating family, having own children, starting career, leading active physical life. At these times plans are set, hopes and future plans are ahead to get fulfilled. Therefore it can be assumed that when RA occurs in non-elderly people they are confronted with challenges that are different from those of elderly people. When the chronic disease emerges at one of these stages it brings disruption in one’s biography. This means that the person should rethink his/her life plans and some of the aspirations might be changed due to the imposed health condition. The process of change itself is challenging.

The prevalence of psychological distress is 20% higher in recently diagnosed young individuals with RA than in a healthy population (Evers 1997). It is important to notice that after emerging RA in lives of adults, old strategies dealing with stressful situations are not appropriate and new coping behaviors are not found yet. An adjustment process has to derive from a patient’s personal resources and will be seen over a longer period of time and at a later stage of the disease (Evers 1997).

A cross-cultural research conducted in the UK and the Netherlands showed that RA has a detrimental effect on many areas of life, including moods and emotions, social life, hobbies, everyday tasks, personal and social relationships and physical contact (Whalley 1997). According to the same cross-cultural research it was common among interviewees to feel angry that they had the condition and many felt as if they were being punished for no reason. “Why me?” is a question which prevails among RA patients. Patients are aware of the progressive nature of the condition. Many fear for the future, the most common concern is that they may experience a complete loss of independence. However, there is also a great sense of taking each day as it comes and not giving in to the condition that seemed to override concerns about the future.

A research done in the Netherlands (Jacoby 2003) showed that the burden for caregivers of RA sufferers is caused by a disrupted schedule and to a smaller degree by a lack of family support, financial problems and loss of physical strength. This study suggests developing support strategies for partners of RA patients, which should focus especially on reducing the burden caused by a disrupted life, and simultaneously on increasing the focus of caregivers on the positive aspects of caregiving.

As research shows that in the Netherlands withdrawal from the labor market is rather high (Chorus 2001). Of the 720 patients, 343 (47.6%) had withdrawn from the labor force after a mean disease duration of 4.8 years; 69.8% of these patients indicated that they had stopped working as a consequence of RA. At the time of the study patients who had left the
labor force had a mean age of 50.1 years. A significantly higher proportion of patients who had left the labor force were women and they were less highly educated than patients who still had paid employment. Furthermore, patients who had withdrawn from the labor force experienced significantly higher disease activity, longer disease duration, and more disabilities than patients still working. These variables are considered as important confounders in evaluating the relation between work factors and withdrawal from the labor force and evaluating coping and withdrawal from the labor force in patients with RA. It is also reported that after a mean disease duration of 4.3 yr, among Dutch patients with RA the adjusted employment rate was 16% lower and the adjusted work disability rate 11% higher when compared with the rates of the general Dutch population (Verstappen 2005). Of the RA population in employment, 37% changed their working conditions due to their RA. Only 18% of the work disabled patients without a paid job were willing to return to the paid labor force.

In the Netherlands, the social security system entitles employees who are on full or partial sick leave for more than 1 year to a work disability pension after work disability is officially recognized on the basis of a medical and ergonomic examination. This pension provides income compensation up to a maximum of 70% of the last income for a maximum period of 5 years. At the end of that period the person’s work ability has to be reassessed. The level of compensation is dependent on age, number of working years, and the level of work ability. Those whose ability to work is impaired by 80–100% are entitled to a full work disability pension while those whose ability to work is impaired by 15–80% are entitled to a partial work disability pension. In the Netherlands it is therefore possible to receive a work disability pension and to remain in employment, usually on a part time basis (Chorus 2001).

1.3 Theoretical Concepts

1.3.1 Anthropology of the body

The sources selected for this review are only a small number of medical anthropological theories, anthropological queries, articles, and findings among the pool of sources. Up to twenty significant articles and several books have been reviewed in order to address and explore theoretical findings in the complex field of chronic illness.

The approach I have used to combine findings out of the anthropological literature was the anthropology of the body, which gives theoretical insights how body and mind are defined by the scholars of this field.
Thomas Csordas (1994) developed a paradigm of embodiment. He argued that the body has a history and it is not only a biological entity but also a cultural phenomenon. He introduced the term “embodiment” which was defined and re-defined many times by scholars. He argues that our bodies are not mere objects but are integral parts of our being, and our experiences of our life are embodied. In short, the concept of embodiment focuses us on how a person’s perceptions are embedded in his/her mind as a reflection of what is “inscribed” on the physical body. Thus ‘embodiment’ offers an important approach that will help to “to reformulate theories of culture, self, and experience, with the body at the center of analysis” (Csordas 1994:4).

Within Csordas’ inquiry about embodiment, it is interesting to see how the mind and the body are involved among chronically ill patients, and how Csorda’s approach is reflected in the embodied perspectives among chronically ill. The body and the mind interact, but how can we study to what extent and what is the order of influence? Does it mean that when the body suffers and is ill, the mind’s perceptual experience [of the society] also changes? I will address this when I will review the experience of chronic pain and relation with self-identity.

Another anthropological perspective “the Mindful Body”, important for this study is presented by Nancy Scheper-Hughes and Margaret Lock (1998). They contributed to the anthropology of the body by introducing the analytic frame of “the three bodies”. The authors argue against Cartesian Dualism, which “artificially” separated mind and body so the mind is without its physical extension. Also, Rene Descartes (1596-1650) dictum: I think, therefore I am (Cogito, ergo, sum) says that the human organism consists of a palpable body and an intangible mind. Descartes reconciles body and soul by locating the soul “in the pineal gland whence it directed the body’s movements like an invisible rider on a horse” (1998:349). Which means that a horse (body) is directed by an invisible rider (mind). The authors argue against this by assuming the body is as “simultaneously a physical and symbolic artifact, as both naturally and culturally produced, and as securely anchored in a particular historical moment” (Scheper-Hughes & Lock In: Van der Geest & Rienks 1998:347).

Scheper-Hughes and Lock consider the body on three levels. The first level is related to conceptions of self, where a person places himself within the surroundings. It is called “the Individual Body”. It also includes “internal and external perceptions, memories, affects, cognition and actions” (1998:356). Questions emerging for this study are how the individual body is considered by chronic illness patients and how their self-perception is changed. I can assume that on this level the individual body with perceptions and self-identity in relation to its surroundings can be considered as the body of the chronically ill.
Further Scheper-Hughes and Lock acknowledged social and political dimensions of embodiment. They describe the next level as “the social body”, which is the state of an individual body applied to the entire society. This body is about how individual bodies relate to social aspects and how they reflect social relations. I regard, to my study it is useful to understand how the social environment influences the person to experience chronic pain and how it shapes an individual’s self-identity. Enquiries in this domain will also answer why stigma is believed to be attached to some visible or invisible chronic health disorders.

The third level presented by Scheper-Hughes and Lock is “the body politic”. They argue that the physical body is regulated by political and social aspects. This level is about the regulation and control not only of the individual body but populations. It refers to the ability to “medicalize” social behavior for instance the power of the state depends on the ability to control fertility or physical potency and other aspects of life. The authors also suggest that “negative social sentiments” (1998:365) can be recast as individual pathologies and “symptoms” rather than as socially significant “signs”. There are constant exchanges of meanings among these three bodies and evoking the role of emotions in connecting them. If we go back to the authors’ argument that the individual body is regulated and influenced by social relationships and politics, then we can use their approach to study how the individual body experiences and perceives influences from social surroundings.

The anthropology of the body serves as the theoretical framework for this research to find out how the body and the mind relate to each other when the body is in constant pain and suffers from RA. According to the theory I can assume that when the body is constantly disturbed and doesn’t function well then psychological and social aspects of self are also influenced.

Here, in this research, I consider that Sheper-Hughes and Lock’s individual body and social body are applicable to consider. I assume that on these levels, the individual body with perceptions, self-identity and social interactions can be studied as the body of the chronically ill. Although I will further question how the young body experiences and interprets the internal and external factors caused by pain.

1.3.2 The experience of illness: chronic pain

The vast majority of chronic illnesses are accompanied by chronic pain. In Anthropology, the studies were done to research the phenomenon of chronic pain and how body is experienced when there is constant pain. The studies showed that self-identity is
concerned. Chronic pain brings chaos in someone’s life, and emotions, attitudes, cognition and actions are affected.

To define chronic pain, there is Jackson’s (1992) referral to chronic pain as to continuing pain that has lost its biological function i.e. it is not biologically useful process which usually indicates the onset of something abnormal in the body. It becomes a problem for a sufferer rather than an indication of a problem.

We use our body and operate with it, we do actions with it, but the body is also subject of our actions. In case of chronically ill patient, who experiences sudden and severe pains for many years, his body becomes as an object “distinct from the experiencing and acting self” (Good 1992:39). Pain is part of the body, part of the self. The self becomes dominated by pain. As chronically ill persons explain, time becomes distorted and its perception changes. Past and present lose their order. Space and time are full with pain. Under such intensive pressure, the will is required to maintain control and maintain the self. During attacks of pain and anxiety, the pain dominates inner time, breaks down the relationship between the self and the world to which it relates.

“When pain is intense, the body dominates consciousness. When pain is chronic, it extends into the world, shaping the world itself. The world of pain becomes a special world, a world largely unshared and unsharable, inhabited by persons who have given up on revealing” (Good 1992:27).

Jackson (1992) continues the same thread of discussion in a sense that pain is regarded as a subjective experience, a feeling we can not observe or measure directly. It is what person who experiences it says what it is. That is why pain is a subjective experience. Chronic illness brings chaos to the life of the sufferer and causes transformation of the self; this is one of the dimensions of chronic pain. Some chronic pain patients describe their pain as an object coming from outside, which is not part of them. But when pain is becoming an everyday part of the life, this relationship is becoming conflicting. Although patients do not want to acknowledge that pain is part of them, they say that their self changed to a new one which is no longer complete. They feel “smaller” or undressed, removed from social roles and positions. Charmaz (1983) mentions that the person may accept pain as we-self, but this fusion is not doubling or expanding the self, but it’s rather a loss of self.

To continue the issue of the interweaving process of body and mind, it is important to discuss Becker’s (1999) findings that chronic pain is experienced as if body belongs to others. Seeing oneself different as crippled, old, infertile etc, creates a sense of disruption.
by itself. The process of redefining and rethinking and where one stands in life is very challenging and complex.

In relation to my study it can be asked how are body and self affected by disruption? Which one is more powerful in influencing the another? Becker (1999) suggests that order begins with the body. The understanding of ourselves and the world begins with our reliance on the proper functioning of our bodies. We carry our histories with our bodies. The past is present in the body that is “embodied”. To study how pain is experienced needs to be based on describing the local world where the main focus should be made on the experiencing pain in the context of family and community (Kleinman 1992).

1.3.3 Self-identity

The existing anthropological studies show that self and identity are under constant threat when an individual is chronically ill. Bury (1982) says that it is difficult to maintain a strict separation between illness and the self. So far, the concept of self-identity has not been studied from the perspective of a non-elderly sufferer with RA.

Reis (2001) discusses the relationship between social images of epilepsy and the self-identity of those suffering from the disease. Her study shows that the individuals who have repeated seizures may have problems establishing their identity. The way this is shown is in terms of “being less than others”.

Adams et al. (1997) suggest that the concept of self-identity must be the most appropriate framework to analyze the respondent’s experiences and to understand why people do or do not accept the label of being “asthmatic” or be labeled in other ways. The loss of self among chronically ill is a fundamental form of suffering. To follow this link it is necessary to bring out Charmaz’s (1983) four main sources of suffering among the affected persons: (1) leading restricted lives, (2) experiencing social isolation, (3) being discredited and (4) burdening others. All these sources show how they affect on the consciousness and in particular the loss of self in the individual. The loss of self is the essence of chronic illness.

Estroff (1993) conceptualized chronic illness in terms of illness-identity relationship. She discusses the role of socio-cultural processes of identity transformation that function as “catalysts of chronification”. Honkasalo (2001) continues the anthropological thread and explores pain experience among pain patients in Finland. In contrast to studies that represent illness as a “biographical disruption”, Honkasalo’s findings show that patients with chronic pain experience “continual” disruption. Pain is one among them. Hence it is
important to see how the author explains experiencing chronic pain among Finnish patients to understand how the self is inter-subjective and is constructed by socio-cultural practices.

1.3.4 Chronic illness as biographical disruption

Chronic illness as a biographical disruption is a considerably new concept in medical anthropology. Chronic illness has to be considered as biographic disruption. The questions about the reasons of illness and about uncertain future have to be answered; Emotional shock, constant pain and fear of disability leads to withdrawal from social life. Professional life is one of the major concerns especially among young patients. It inevitably involves disruptions in material and practical affairs.

Bury (1982) underlines three aspects of disruption: (1) “taken-for-granted” assumptions and behaviors, (2) re-thinking of the biography and self-concept, (3) mobilization of resources. At the first stage of onset when the individual must recognize the illness as illness, it is impossible to think about moving from one status of being healthy to another one of being chronically ill. The illness often is not disclosed to others due to the expectations associated with the status of being chronically ill.

When people’s health suddenly disrupt, they are thrown into chaos. But how do they create meaning in a chaotic world? Becker (1999) argues that people attempt to create continuity after an unexpected disruption of life. An illness is a major disruption to person’s biography. When the body is in chaos, one’s sense of wholeness disintegrates. There can be the threat of death temporarily, and sometimes permanently, it definitely destroys people’s sense of order. Daily life revolves around what the body can do, that is why body is unpredictable when it is disrupted. After disruption people have to rethink and make necessary alterations in their daily lives. Becker (1999) suggests that it is not possible to move on with life until the future is reorganized and the new meaning is given. The restoration of normalcy includes the preparation of a place in life with hopes and dreams and they must be acceptable and they have to be incorporated into new identity. The bodily changes are an integral part of this process. The mind has to adjust to the requirements of the body, listen to the body and carry out routines and activities. The old self changes and the new self takes over, which is a difficult process but nevertheless necessary. According to Becker, continuity in life after one suffers from chronic illness, is an illusion, it is more a biographic disruption! According to the theoretical concepts stated above, I will study that chronic illness such as RA affects non-geriatric patients differently then elderly people. It affects young sufferer’s emotions, social relationships, employment, future plans, and
brings sudden changes due to moving from the status of “being healthy” to the status of “being chronically ill” at a younger age.

1.4 Objectives of the study

The aim of the research is to explore and describe the non-geriatric respondents’ own experiences and explanations of how they live with chronic medical condition as rheumatoid arthritis and chronic pain which is one of the major symptoms of the RA; how their body responds to chronic pain, how their psychological and social well-being is concerned. This research will show how these interpretations match the theory of the body and self identity. I base my approach on the theory of embodiment where pain is experienced and exists in the body in a social, cultural and historical context.

1.5 Research questions

In order to meet the objectives of this research, it is relevant to answer the following sub-questions:

1. What kind of transformation takes place in young people’s psycho-social domain when they are affected with RA?
   1.1 How does chronic pain affect psychological well-being from the perspective of individuals living with RA, in particular, where self-identity is concerned?
   1.2 How does chronic pain affect social well-being from the perspective of individuals living with RA?

2. How do young people affected with RA interpret their illness?
   2.1 How do young individuals affected with RA perceive changes when moving from the status of “being healthy” to the status of “being chronically ill”?

1.6 Limitations of the study

This research was planned and organized during a six week period. Taking into account these time constraints, it was evident that this research would cover limited aspects. Some aspects were known from the beginning but some emerged during the course of the fieldwork.

I initially planned to maintain a strict gender balance by interviewing equal numbers of respondents of both sexes. Due to time pressure it became quite difficult to keep this
promise. It is my understanding that the studying gender differences among RA affected individuals would shed light upon on aspects how both sexes differ in experiencing this chronic medical condition and if they do, in what aspects. And eventually by understanding the daily challenges of being a man with RA and of being a woman with RA is a necessary step in the effort to help dealing with and overcoming those challenges. Since the study had to be completed in six weeks, it became difficult to search for more male respondents.

Time pressure also prevented me to establish contacts with close family members of my respondents. My research will talk about how my respondents see themselves through the eyes of “others” and similarly it would be valuable to explore how “others” experience my respondents with their daily ups and downs. And simply to explore what aspects of social relations are deeply affected by living with RA. Due to time limitations this part of the research was not explored the way it was planned.

I also considered the need to explore the issue of stigma among my respondents who represent a non-geriatric age category. The reason is that this aspect has been superficially understood in this age group with RA. And also, I presume that their experiences have been generally overlooked. Due to time limitations this aspect of the research was not studied.

Another limitation in this research is the fact that the initially planned focus group discussion among the respondents had not been arranged. My respondents were located in different towns in the Netherlands and I had to travel to reach them and due to distance it became impossible to gather them in one location for a meeting.
2. Methodology

The theory of embodiment, employed in this research as a theoretical concept to support the findings, suggests that our bodies are not objects to us, but an integral part of our being. Experience of life is mediated through our bodies (Csordas 1994:39). Hence, I presume that if the body is in chronic physical hardship, then other aspects that are influenced by our embodiment such as self-image and social relations must be challenged as well.

The focus of this study is to describe what RA affected individuals think about their experiences, how they relate to their experiences, how they reflect on their bodily hardship, what it means to them to be affected with RA. The aim of this study is to explore the meaning of being affected with rheumatoid arthritis. This study is focused to investigate psycho-emotional and social aspects of the disease, but also addresses mechanisms and strategies how these individuals manage their daily lives.

2.1 Study type and design

The research method which is used in this research is qualitative. The main objective of this study is to explore and describe people’s experience when they are affected with RA. It is considered to be an exploration because the presented topic has not been addressed in the way as it is proposed in this research. This research was to “gain insight into a problem by investigating people’s views on the problem, how people interpret the nature of the problem, and how they seek solutions” (Hardon et al., 2001:178). Hence, the research method applied in this research was exploratory and qualitative by nature, the aim of which was “generally to seek answers to questions about the “what”, “how” or “why” of a phenomenon, rather than questions about “how many” or “how much” (Green & Thorogood, 2006:5).

The study, as a qualitative research combined study types, where an exploratory and descriptive study types were used. It focused on the micro level since explored and investigated people’s views and their interpretation of the nature of the problem and how they managed to adjust to life challenges. This was achieved by interviewing the number of informants from the target group and open research techniques were applied. To explore what meaning people give to their experiences to chronic pain, I have developed a number of specific topics based on the research questions (see Annex).
2.2 Study population

The study has been conducted among Dutch people suffering from RA over the period of six weeks. Overall ten RA affected individuals were reached and interviewed. Besides one doctor and one nurse also shared their experience. The sample did not intend to be representative of all adult population affected with RA and living in the Netherlands. A convenience sampling method was used to select potential respondents. For the purpose of the study age range was between 25 and 50 years old. Besides age group the inclusion criteria was to be currently on treatment and be able and willing to conduct a conversation in English.

In order to find respondents for my research I have contacted various medical institutions specializing in immunology or had rheumatology department in their facilities. One of them were the Jan van Breemen Institute (JBI) located in Amsterdam which is a specialized medical center for treatment, research and rehabilitation of patients affected with different types of arthritis. The JBI has an assessment center for diagnostics and offers complex multidisciplinary treatment to the patients. The programs at the JBI widely assist patients in preventing further complications and has effective programs in rehabilitation. Their educational courses, research and care programs meet the needs of people affected with different types of arthritis. The JBI also has an information center and a library where interested patients and researchers can obtain information about rheumatoid disease and all the issues related to it. Further information is available on their web-site at www.janvanbreemen.nl A rheumatologist doctor at the JBI kindly assisted me in contacting RA patients.

Five out of ten of my respondents are undergoing treatment at the JBI. They met the selection criteria of my research. I phoned them and asked if they would like to be interviewed about their experiences, feelings and thoughts. To my delight all of them were very keen to participate in my research.

Considering the selection criteria and time constraints of the research, I had to look for other options to find my respondents. My search brought me to the world wide web which found quite efficient way to reach these people. Internet communities are important sources used by people living with different health conditions. There are several websites designated for or run by the people affected with RA. The most informative web-site I found was the site of The Dutch Arthritis Association (Reumafonds), which is the largest independent fund of arthritis research in the Netherlands funding around 70% of the arthritis research in this country. Their site www.reumaresearch.nl contains valuable information on current researches and educational material for the patients. They also facilitate patients to
meet on-line and exchange their thoughts on various topics including treatment, advice, education etc greatly assists the increased social participation. One website is run by two arthritis sufferers and seems quite popular according to the number of visitors and participants in chat rooms. The objective of this website is to provide further information to people who may need additional information and/or just want to socialize with people who face similar problems. Five respondents were contacted, met and interviewed from this and other websites. At the end, the snowball technique found very effective to reach my respondents (Hardon et al., 2001:267).

2.3 Data collection techniques

Validity of the date was maximized by combining different techniques in the study. Triangulation was ensured by comparing data for inconsistencies. The following tools were used for data collection in the study:

1. In-depth interview with the respondents
2. Interview with the key-informants

The main data collection technique I used in this study was interviewing respondents. Interviews with ten respondents were conducted during the six week period. The respondents lived in different towns in the Netherlands so I had to travel to reach them. All of them spoke very good English.

I started the research with interviewing a key-informant who is the specialist in the field of rheumatology as to obtain more information on various aspects of the investigation. A high degree of flexibility was achieved by using semi-structured and unstructured questionnaires. The order of asking questions was flexible. The questions were open-ended in order to allow the respondent to use their images, feelings, thoughts, experiences and reflect on them. Initially, after introduction and talking about the disease history and obtaining basic information from the respondents, I was asking the same questions prepared according to the research themes. I also asked additional questions if more in-depth insight on the subject was needed.

Reliability of the research instruments was improved by designing more precise and unambiguous questions. A pretest interview had increased the reliability of the research tool. The questions were pre-tested with one respondent who was affected with RA but did not fall in the age category of this research. With this pretest I determined the issues including the relevance of all the questions, the sequence of questions, the correctness of
language, following the time, the need for instructions for the respondents (Hardon et al., 2001:302).

2.4 Data processing and analysis

A qualitative analysis was performed. The process started when I transcribed all the interviews from the tape and read carefully. I performed open inductive coding first when I used emic and descriptive codes. Data were analyzed manually. After initial coding deeper analysis was done including searching for common patterns, comparisons, connections to theory, deviant cases and developed themes and sub-themes. Whenever necessary, I created tables, matrixes or diagrams to visualize and categorize data and findings. Data was analyzed according to the rigorous general principles of qualitative analysis (Green & Thorogood, 2006:191). Validity, reliability, reflexivity and transparency were thoroughly checked and maintained throughout the research process.
3. Respondent profile

This chapter will provide an overview of the basic information of the respondents. After introducing the purpose of the interview and talking about ethical aspects in the research, the interview started with questions regarding demographic information which included their age, marital status, number of children, education level obtained, previous and current occupation.

3.1 Respondents’ age, gender and age of onset of the RA

There are ten respondents in the research. The age of the respondents varies from 37 to 52. There are nine female and one male participants.

<table>
<thead>
<tr>
<th>Age of respondents</th>
<th>Gender</th>
<th>Age of onset of RA/Years lived with RA</th>
</tr>
</thead>
<tbody>
<tr>
<td>37</td>
<td>Female</td>
<td>33 /4</td>
</tr>
<tr>
<td>40</td>
<td>Female</td>
<td>16 /24</td>
</tr>
<tr>
<td>42</td>
<td>Female</td>
<td>24 /18</td>
</tr>
<tr>
<td>43</td>
<td>Female</td>
<td>38 /5</td>
</tr>
<tr>
<td>43 (S)</td>
<td>Female</td>
<td>21 /22</td>
</tr>
<tr>
<td>45</td>
<td>Female</td>
<td>35 /10</td>
</tr>
<tr>
<td>45 (D)</td>
<td>Female</td>
<td>41 /4</td>
</tr>
<tr>
<td>46</td>
<td>Male</td>
<td>41 /5</td>
</tr>
<tr>
<td>47</td>
<td>Female</td>
<td>25 /22</td>
</tr>
<tr>
<td>52</td>
<td>Female</td>
<td>32 /20</td>
</tr>
</tbody>
</table>

The mean age is 44. The age of onset of RA varies as are years lived with RA. The mean years lived with RA is 13.40.

3.2 Marital status

Out of the ten respondents, four respondents are married, two are divorced, three are single and one lives with a partner. One of the divorcee now has a long-term boy-friend, another divorcee was married for two and a half years and since then had two very short-term relationships. One single respondent is also a single mother and never had a partner. One respondent lives with her partner for fifteen years.
<table>
<thead>
<tr>
<th>Marital status</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>4</td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
</tr>
<tr>
<td>Single</td>
<td>3</td>
</tr>
<tr>
<td>Living with partner</td>
<td>1</td>
</tr>
</tbody>
</table>

### 3.3 Having children

Out of ten respondents, six have children and four don’t have children. The only male respondent has three children, the others are mothers of one child. One of them adopted a son. One single mother had her child through IVF.

<table>
<thead>
<tr>
<th>Having children</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>With child</td>
<td>6</td>
</tr>
<tr>
<td>Without children</td>
<td>4</td>
</tr>
</tbody>
</table>

### 3.3 Occupation

Among the ten respondents, we find a doctor, an engineer, a police office employee, a factory worker who is also part-time nurse in an elderly care home, a business woman, a journalist, and four of them who have a severe form of RA are getting a disability pension. Among the respondents only three maintain full-time jobs and three are employed part-time. Those who maintain full-time jobs now are considering shifting to part-time positions, change location and adjust their career to their health condition.

<table>
<thead>
<tr>
<th>Present occupation status</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>1</td>
</tr>
<tr>
<td>Engineer</td>
<td>1</td>
</tr>
<tr>
<td>Factory worker/part-time elderly care nurse</td>
<td>1</td>
</tr>
<tr>
<td>Policy department administration</td>
<td>1</td>
</tr>
<tr>
<td>Journalist</td>
<td>1</td>
</tr>
<tr>
<td>Business woman</td>
<td>1</td>
</tr>
<tr>
<td>Disability pensioner</td>
<td>4</td>
</tr>
</tbody>
</table>
3.5 Treatment

When interacting with my respondents, I was starting our conversation with questions leading to learn about their disease histories including information about how their disease started, how old they were at the onset, how it progressed over years and what kind of treatment they were undertaking.

<table>
<thead>
<tr>
<th>Respondents</th>
<th>Age of onset of RA</th>
<th>Years lived with RA</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>16</td>
<td>24</td>
</tr>
<tr>
<td>3</td>
<td>24</td>
<td>18</td>
</tr>
<tr>
<td>4</td>
<td>38</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>21</td>
<td>22</td>
</tr>
<tr>
<td>6</td>
<td>35</td>
<td>10</td>
</tr>
<tr>
<td>7</td>
<td>41</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>41</td>
<td>5</td>
</tr>
<tr>
<td>9</td>
<td>25</td>
<td>22</td>
</tr>
<tr>
<td>10</td>
<td>32</td>
<td>20</td>
</tr>
</tbody>
</table>

The table shows that the participants’ mean age in this research study is 44. The age of onset of RA varies. The number of years lived with RA also varies. The mean years lived with RA is 13.40. The four respondents, who are on disability pension, were diagnosed with RA 18, 20, 22 and 24 years ago. One more respondent was diagnosed with RA 22 years ago at the age of 21, she tries hard to stay active and balance her disease and a part time job despite many surgical involvements and other problems related to her health.

My respondents had different onsets of the disease. Some of my respondents said that it took several years for doctors to determine why pain in their joints were occurring and disappearing. Often doctors suspected that it was RA, but they could not prove with the laboratory tests. Some of the respondents were guessing that their pain was early signs of RA since they had family history of RA and that’s why they were familiar with symptoms. For some of them it took years to properly accept the diagnosis.

Pain of different severity and frequency, tiredness and fatigue are constantly present symptoms when having RA. These symptoms are an integral part of the disease but not the only indications of its presence. Pain starts either slowly or suddenly in their joints. The patients have “weak” spots in the body which are initial areas of inflammation. As one of my respondent (43 years old) said, this is how RA started:

“I always complained about my feet. It started earlier when I was a teenager. Nobody ever thought that it was arthritis. Well, many children have problems when they grow up and that’s why it was not suspicious what it was. And I
wore orthopedic shoes. My toes, ankles and heels ached. I could not move easily. It did not happen every day and that’s why they [doctors] did not diagnose me with arthritis. It is possible that it [arthritis] was already there. I also had problems with my shoulders but it was not constant. After this I got inflammation in my hands and then I have changed my doctor. He was the first who took my blood test and did research about arthritis, because he suspected that it was arthritis. Then I was 21 years old.”

Several my respondents mentioned that the onset of the disease was sudden and very painful. One of them (37) who worked as a doctor had to quit her job and move into medical research. Now she has a more flexible part-time position as a medical researcher. She recalled:

“It [RA] started suddenly in all my body, it was everywhere… In shoulders, ankles, fingers, my toes, jaw bones, joints. I was so bad…. I felt sick, so I immediately had to stop working, I worked as a GP and could not sit at the desk and treat other people and simply talk with my patients. I was sick all the time, I could not continue any more…”

It usually take a few months to find out if most RA treatments are suitable for a person. The reason is that people respond to these particular medications differently. One medication, which effectively treats one patient can be found as a counter-indication for another patient. In the meantime people often need some relief. One of the first recommendation to my respondents by doctors was to control pain, which would allow them to function at a normal level. There are various medications usually prescribed to the patients. As my respondents reported, some of these medications are really helpful and relieve pain but they are a fast-acting treatment for the symptoms, but not good as a long-term treatment for the disease. After this stage when pain can be regulated with medication, doctors prescribe long-term treatments. Not everyone responds well to these prescribed medicines. Some of them experienced various side effects and mentioned that the problem of side effects is bigger than the RA itself. Some prescribed medicines are those which are given to cancer patients, but in higher doses. RA patients receive them in a very low dosage. Knowing this fact was frightening for my respondents. All my respondents were undergoing medical treatment, but three of them preferred to take other herbal supplements or homeopathic remedies to boost their immune system against the disease. All the patients take conventional medications especially for RA, but some of them have had excellent relief from antibiotic therapy using derivatives of certain antibiotics. The key-informant mentioned that he doesn’t advise his patients to use only alternative forms of medicine because in the meantime, the patients may lose time and their condition might get worse.
4. Living with rheumatoid arthritis

4.1 RA effects on the body and psychological well-being

4.1.1 Bodily changes

Almost all my respondents experience pain in their joints in different parts of the body in varying frequency. Sometimes pain starts only in some parts of the body, sometimes altogether in all joints. They feel very tired and want to sleep. Pain can be tolerated, but it is very annoying. Many of them take strong medications to control pain. Sometimes their pain is so strong that strong medications don’t help and they have to manage their pain by applying warm pads or ice packs on inflamed joints. During this period they are less functional and are mostly concentrated on managing their pain in their own way. Nine out of the ten respondents are women. They mentioned that their pain gets worse two weeks before their menstrual period and they think that it could be related to the hormonal changes in the body.

An active period of flare varies in every respondent. It might continue for several months, it may start suddenly and go away soon, or might start slowly and stay for a longer period. Some of the respondents mentioned that their pain can be triggered by the changes in barometric pressure. All of them perceive and describe their body in different terms, but the common thing is that the body is always there reminding them in a very painful way. As one of the respondents (42) who was diagnosed with RA 18 years ago and had knee replacement and wrist joint removal surgeries mentioned:

“I am constantly aware that I have a body, it is present, it is here. It is like constant feeling of presence! It is like you feel heartbeat everywhere in every part of the body!”

Another respondent (45) who was a professional performer of modern and classic dance had to quit her career as a performer and now she is a journalist and writes about dance and other forms of performing art. She mentioned that this transformation from a status of being a healthy person to a status where she is restricted in doing her favorite activity is very painful and she has to put much effort into going through this process. She said that when pain comes she thinks that her body is old:

“I see my body older than it should be at my age! Because it can’t move fluently as it should! It [body] makes me move as older person! I see myself getting up, standing up, going from point A to point B and do it as an older person. So I
perceive my body as being old. When I compare my background and age to other people, they do phenomenal things with their body and they don’t have any arthritic problems! And none of them have any complaints. I feel very limited! And I feel older in comparing with people of my age! This is what makes me think like that. And sometimes I walk like 80 year old woman. Really! And I think, oh, my God I walk and I am like old woman.

Most of my informants emphasize that they can’t function normally anymore and feel themselves as being heavier; they can’t do physical things and maintain control over their body as before. The same informant mentioned:

“I am heavier now. I can’t dance any more. I can’t do things to stay fit, slender and beautiful because it hurts too much. Now I have a job where I sit most of the time, I do yoga but it is not that rigorous work”.

As all my respondents mentioned that pain is ever-present in their lives, it’s there all the time in the background and as one of them said it’s part of her life. It is very difficult to carry, but there are good periods and bad periods as well. Living without pain became unimaginable for some of them; several mentioned that they don’t know how it is to live without pain.

Since they were diagnosed with RA their bodies have changed. Those respondents who have had severe form of RA for more than eighteen years, have visibly deformed bodies. Their hands and feet are mostly affected and in case of a far advanced form of RA neck, knees and hips are severely damaged. Areas around the joints are swollen and sometimes red.

One of the respondents (43 (S)) mentioned that she get used not only to this pain but also to surgeries on her hands and feet. These operations have become usual events for her. She had been living with RA for twenty-two years. She said that she can tolerate and ignore pain only when she works at the office. But at the end of the day the worse part comes. She describes how she perceives her body:

“I think that it [pain] is never goes away. At that moment I don’t like my body. I don’t think I look beautiful or attractive or useful [laughs]. I feel clumsier, I am not flexible, I don’t move easily. I found myself restricted. So, when there is a party, for instance, you have to think go or not because later your body will be hurt. You don’t do things spontaneously. When you do spontaneously, without thinking, then your body calls you back. I think, I live like a prisoner with the heavy steel ball attached to my feet. You can’t loose it. It’s always there. It’s burden and sometimes I say to people around me that my greatest wish is to have a day or two to be without pain. Because I can’t remember how it is [it started 22 years ago]. So to me it seems it should be very nice [laughs]".
When my respondents were trying to depict how they perceived their body, they were talking in negative terms. The next female respondent (43) said that during painful periods she doesn’t like her body and that she is sorry about it:

“Before it was just the whole body, now I feel like I am splitting in two; one part is in pain and doesn’t want to do anything and another part still wants to go on, but it is not still possible. Both parts are mine, but one part I like and another hate, because I can’t do whatever I want to do. I am getting upset on my body, because normally I can do everything with my body and could do everything I wanted but now not any more! I am upset: why it happened with me?”

The next description about how body is perceived when experiencing constant pain shows how the person (45 (D)) can be related to her own body:

“I think it [body] cheated me. It left me alone and it let me down. It is not with me. Because your body is something we need to have normal life, now when you have pain you think that your body lets down. I wish I was in another body at that moment. I am happy if I don’t have pain, my mood is good. I can do something nice with children ... go out…. But I only want to sit down when pain is there, I am tired, and only want to sleep.”

The same respondent clearly sees and remembers experiences with her body when she was free from RA. She was diagnosed with RA four years ago and it seemed to me that the shock of the first diagnosis was still present in her life:

“When I was well ... I could wear shoes on high hills. Now I have to wear flat shoes. Before RA I wanted to treat my body with something nice. Now I don’t want to buy new cloths any more…. Now I don’t care because I think less about my body….I don’t have energy for that and also it is not important for me anymore”.

The next female respondent, (40) who was diagnosed with RA twenty four years ago and is confined to a wheelchair, knows her body very well and despite having lived with pain for so long she still gets irritated and gets angry about herself. She doesn’t hate her body but gets cross and cries over the fact that she has overdone things and it has provoked pain. She already feels her body and knows how to prepare herself for pain attack which may last for several days. When I asked her to describe how she perceives her body during pain period, she compared it with the situation when we feel that danger is around and we summon all our survival skill to resist:

“when pain attacks, it is like when you feel that the burglar is somewhere around and you look around, you are scared of something of what you don’t know, your body tenses, something dangerous is around and you expect something worse. You expect sirens every time, you prepare yourself for that noise, you go on alert, you
tense up, you transform and you focus your mind…I think it is something what your body does automatically for something worse….”

The respondents complained that RA affects their daily physical activity. It is difficult to start every single day. It takes time and lot energy for them to get out of bed and get ready for the day. Grabbing bed sides and making several efforts to leave the bed is difficult for all of them. All my respondents are eager to follow their old pattern of life: go to gym, do housekeeping by themselves, do some activities at home, but pain is so bad that they have to refrain from doing them. Four of my respondents who are on disability pensions have home care service provided by the health care system. Despite the fact that this care is very helpful for them, they still find it difficult that they can’t do these activities by themselves. One respondent (52), who is on disability pension said that she turns her back not to watch how home care person cleans her windows. She still wants to do it by herself but she can’t.

The next person (46), who is the only male respondent among the ten, was diagnosed with RA five years ago. When I asked how he perceives his body he answered that he thinks in terms of action and doing things rather than feeling. From this statement we can also see that the person may can’t control himself and knows about it and that it comes from the pain not from him. He describes:

“When pain comes, I feel very bad [repeats 3 times]. In the beginning I am very angry, all my plans are falling into water. What I planned to do at home or with my kids turn to almost nothing. Then I close myself. During pain, any normal thing what I do every day is almost impossible to do. That moment I try to do everything what I did before, but when I can’t do what I needed to do then I start talking loudly and become irritated on any simple thing. I explain to them [family members] that it is from the pain not from me.”

All the respondents mention that they have become physically restricted. Even doing the smallest things with fingers which requires concentration is not possible any more. Holding something in their hands, opening jars and other similar things cause pain and irritation. Going to the gym and following fitness regime needs to be done very carefully because once you overdo it you may suffer from consequences by having severe pain afterwards.

In this subparagraph I wanted to show how my respondents describe their body when it is in pain. Most of the respondents don’t find it easy to distinguish their thoughts about their own body and feelings and emotions when pain strikes them. As all of them told me they never paid attention to their bodies in terms of accentuating its physical image. Most of them said that the body is “a place where there is pain” and “unpleasant things are
happening." None of my respondents seemed happy with their body. Also as they mentioned they never thought about it in terms how it was asked during our interview.

In the next sub-paragraph will be described what kind of feelings and emotions are evoked by constant bodily pain and changes in the body.

**4.1.2 Feelings, emotions and chronic pain**

At the beginning of my research I questioned how chronic pain is experienced and embedded in people’s feelings and emotions. As Jackson (1992) discussed, pain is regarded as a subjective experience, a feeling which we can not observe or measure directly. It is what a person who experiences it says what it is. In my research, I decided to explore the subjective experience of the people who experience daily pain that is associated with their medical condition such as RA. Because of its subjective nature, I assumed that people develop their own patterns of “pain experience”.

Interviews held with my respondents made me aware that for some people it was not easy to talk about their emotions and feelings. Maybe because of the fact that talking about something negative which is actively present in your life may evoke negative feelings again. It could turn into a traumatizing event, but during the course of the interviews I noticed that it was not the real reason. I found that my respondents had not done this type of interview before and also talking with a stranger about personal experiences was not common for them. At the end they mentioned that they even liked it. Sharing was found to be a very rewarding experience for both sides.

From the stories of my respondents, I observed that there is a general pattern of feelings and emotions that occur in my respondents’ experiences. These feelings mostly are negative and are closely linked with experiencing constant pain. Almost all the respondents replied that they are often annoyed, frustrated and irritated. But it also became evident that there is a factor that vastly influences formation of the personal experience. It is their character.

My respondent (45), a middle age women said that when she is in pain, she sees herself as an old woman. She has to listen to her body and make appointments and other obligations according what her body will allow. She sees herself smaller, minor and unattractive. She describes how she feels when pain comes:

“I feel annoyed, frustrated, irritated and I am trying to ignore it and just carry on. I lose my breath. And it makes me more vulnerable, because I know that in that particular situation I have to leave the place and run home. Also, I have to be more conscious”
when making appointments, because then I don’t want to be late and make people wait for me. There is always an element of coping in every situation. You try to avoid awkward moments and it makes you vulnerable, or managing, or not to be too involved! I feel less as a human being, because I can’t function normally!"

My respondents who maintain their jobs report that they have to struggle every day in order to balance their social lives and physical pain. This happens at the expense of emotional and physical waste. One respondent has constant feeling of frustration and disappointment. Stress has become common in her life. The same respondent mentioned:

“I loose my temper more easily for number of reasons: my life is stressful enough, I teach at the university, I write articles for the newspaper and other publications for other sources in the world and pain of top of that… it just exacerbates stress that you already have. So I am stressed to handle too much and pain makes it worse, now I have to have hip surgery… and then I loose my temper easily and I have trouble to concentrate. Concentration is difficult. I can raise my voice and can yell at people and at my partner … he suffers the most [laughs].”

Another respondent (42) who had knee replacement surgery described how RA changed her emotions for the worse and admits that they affect her family happiness. She seemed quite concerned about it. But at the end said that she is confident about her husband’s understanding and support. She mentioned:

“Before RA I was not emotional at all. After [RA] my moods and emotions are up and down. Now I can be really angry, I can cry and my emotions are more intensive now! Sometimes I can handle it very well and say …well, it is as it is, but sometimes I am very sad and think why it does not stop ever? Why it is going on and on? When the doctor confirms about new problem, I am angry, sad, unhappy and moody I can become easily angry and have no patience with myself and my son and my husband, they are mostly affected [laughs]. For example, when I have pain free period, I can be more patient when my son is noisy, but when I am in pain I can raise my voice to him.”

A male respondent (46), who was diagnosed with RA 5 years ago, is happy with the fact that his body responds well to the course of treatment and said that he gets depressed when pain starts. He becomes sad, emotional, quiet, and also angry about any small problem. He talks about his future in negative terms and seemed anxious and uncertain about it:

“I don’t know how it is going to end. I started with light medicines and now I am using stronger ones. It means that it became worse. Before I was still emotional by nature, but then I was stable. But now I have to ask for help and it makes me very sad….I don’t want to ask for help, but I have to…”

Body on Alert! Living with Rheumatoid Arthritis: Non-geriatric Individuals in the NL, by Nino Gurgenidze
The narratives of my respondents show that RA evokes negative emotions when the normal rhythm of life is compromised and they have to change it. Suddenly they have to change home mobility and social mobility. My respondent (45(D)) seemed unhappy and depressed. She said:

“I am tired. I feel very irritated and angry because when I compare when I did not have this RA I could do everything. I was energetic. Now I can’t open the bottle, I become very irritated. I think if I wouldn’t get the sickness I would go on a vacation, I can’t do it anymore… Sometimes I think I don’t want to live anymore… “

I found that negative emotions can affect not only the mood of this respondent, but also her health in terms of not following the prescribed course of treatment. The key-informant confirmed that adherence to the treatment is thought to be very important for RA patients. One of my respondents mentioned that:

“Because you are going into depression, you feel yourself miserable. I don’t not take my medication the whole day because I am stressed. I think to take it when I come home, but when I come home then I forget it and then everyday I skip and skip. I feel that my life is going down.”

I asked my respondents to describe what particular issues were making them very sad and depressed. I found similarities in their answers. Surprisingly, one of them was a visit to their rheumatologist. Regular check-ups were mentioned as challenging experience to face. During the visit they once again had to face their diagnosis. The nature of RA is irreversible. It may go into remission but it may also progress rapidly. Before the visits some of my respondents already have doubts about emerging new problem, but when the doctor confirms that doubt it is double annoying. In that case they feel that the visit is loaded with heavy feelings. The next respondent (43) recalls:

“Now it is easy for me to cry, but normally it was not like that. When I leave doctors office I get very upset with the situation [new problem]… I sat outside the office and cry. So I never did it with many people around.”

Another respondent (43(S)) said that every visit to the doctor brings stress and disappointment. She described that over they years she has had several surgeries and after every operation she hopes that the problem is over for good. But right away her rheumatologist mentions that she has to prepare herself for the next operation. She mentioned that it is very stressful for her. She always knows in advance what doctors are going to say, because it seems that the doctor confirms her doubts. Other respondents said that they feel down when doctor recommends that they increase the dosage of their
medication. When interviewing another respondent (45(D)), I felt she was in the biggest despair. She was told that the medication she was taking at that time caused changes in her blood formula and had to switch to another one. That change was very scary experience for her:

“I always know exactly what they are going to say to me because of my pain and the way I feel that time. Then I am down, with very heavy feelings...”

Another respondent made interesting remark that there is one thing which strikes her every time the rheumatologist writes in her medical history. That is wording: “severe form of RA”. It is always shocking for her even though she is disabled and has known it for many years. Disappointment, sadness and frustration are very frequently experienced by the next respondent (52). She referred that the fact that she is disabled makes her to feel down. But hates that feeling because she wants to do things but can’t. She tries to stay socially active, for example, she goes to her son’s football game where she stands on her feet for hours and gets pain in the evening, but she still does it:

“I feel angry to myself because I am in pain and not because I have overdone something. I can’t say that I am completely depending on things. But there are things like making cup of tea which makes me tired and this is very sad...”

My next respondent (40) is always irritated when pain strikes and it lasts for several days. She has already experienced pain for twenty four years and knows how to prepare herself emotionally. During that period she can’t stand noise and light and the only thing she can do is to go to bed. Sometimes when the pain is too bad she cries, but always hopes that it will go away. Sometimes she calls herself stupid because she overdone something.

Through the narratives of my respondents I tried to show what emotions and feelings were generated when the person is disturbed by chronic pain. I also tried to find out how these feelings were expressed and described by my respondents. After talking and interacting with them, it seemed to me that the personality and the character of a sufferer are very important factors. They vastly influence the nature of emotions and feelings. For example, my informant (43(S)), who impressed me with her story of suffering over many years and with her courage and endurance to go through endless procedures and bone replacement operations, maintains her high spirit and strong will and never mourns more than several hours. It usually happens when she visits her doctor. Another respondent (45(D)) who had lived with RA for five years and seemed visibly disturbed and depressed about it, said that she sometimes refuses to take medicines and
doesn’t want to live any more. Indeed, there is no intention to compare my respondent’s cases to each other, but my impression is that personal strength and determination are positive factors to lighten the burden of RA.

Social burden can also exasperate feelings and emotions of a RA sufferer. Some of my respondents indicated that they are getting more painful periods after they have been under stress and pressure. Low income and social problems are directly related to my respondent’s (45(D)) stress level. She is a single mother of two and has to financially support her family. Now she is studying to undertake exams for obtaining a certificate in pharmacy. Her intention is to change her specialization. She wants to work in a pharmacy shop and hopes that she will not have to stand long hours on her feet and will be allowed to work part-time. Before our interview she took the test and apparently was not happy with the results. It was one more reason for her to look unhappy and feel very depressed.

In the next paragraph I will try to reflect more on the narratives and describe if deeper layers of human personality are involved when body suffers.

4.1.3 Perception of Self

Bury (1982) says that the sudden onset of chronic illness affects all aspects of a person’s life. The concept of self and identity is in constant threat when a person is chronically ill. Adams et al. (1997) suggest that this concept must be the most appropriate framework to analyze the respondents’ experiences and to understand why people do or do not accept the label of “being” sick rather than “have” sickness. The authors suggest exploring how chronically ill people manage to reconcile their self identity with other social identities.

My interest in this research is to focus on how onset and progress of RA affects the self-image of a sufferer. My respondents’ age category is non-geriatric and all of my respondents found are middle-aged. Through the narratives of my respondents, I will try to answer how the attack of chronic illness can compromise perception of self. I will also try to explore whether character is changed and how attitude towards life in general can be affected.

Perception of self is one of the formative aspects of self image. To study my respondents’ self-image, I asked them various questions on their character, new qualities in their character, whether they felt the same or different over years, how their attitude to life is different? When I analyzed the narratives, I came across the fact that in general terms most of them answered that they were the same and their personality and their character has not
changed. Although when we were proceeding along the interview, each of them provided me with their stories which talked about big changes in their self.

Despite the fact that all of my respondents have various health problems related to RA and have to face and endure surgical procedures, none of them considered him/herself as sick and dependent. All of them were talking about being normal and independent but later, during the interview they started mentioning how RA deteriorates their quality of life and how they react to these changes.

In general, all my respondents talked about how they are patient and can endure strong pain over years, but on the other hand they mentioned that they became impatient and can get easily angry. My respondent (43) mentioned that:

“When I am in pain I try hard to resist, but … I think, I changed because I don’t have patience with things any more.”

A commonly observed tendency among respondents was the fact that they found some new qualities in their character. Now they think that at some point they are stronger and at some point they are not. Some of them say that their character has changed a lot:

“I suppose my character has changed, but it’s difficult to say how. I always was serious type, I am still! But I think I became less spontaneous. When I was young it was easy to do things, you did not need to think first and do later. I have to plan now. I think I am less joyful. I am busy with my disease.”

Another respondent (45(D)) thinks that her character has changed in a way that it is opposite to the one she had five years ago. She is less willing to help others:

“Before when someone asked me to do something I always did, but now I do it less and less, I think about only myself because during the period when I am sick my mind is concentrated on my pain.”

There is a new quality that my respondent (45) found in her character:

“It is more empathy and understanding for other people with physical illness. Especially when I see elderly people struggling in the street, I think “it could be me”. I more empathize them and now I see their problems more.”

At the same time another respondent (40) stressed that now she is tougher to the world and doesn’t take anything for granted. She appreciates life more and wants to enjoy every day. As my other respondent (37) said, the disease is something which sets its own priorities in your life and you have to listen to what is happening if you want to survive. She said:
“In life there are things that you can’t arrange. RA is something that came to you and you can’t control it. I realized I can’t control it and now I try to be less control “freak”. I became relatively less controllable, before RA happened with me, I thought if you want something to achieve you can do it but it is not that black and white… and after the first period of pain I thought there is more that you can arrange…”

Another general pattern in my respondents’ narratives was that RA can change one’s self-esteem. They always say that their self-worth has not changed, but in their stories there are statements which indicate that their self is estimated lower than it was perceived before. My respondent said:

“Before that [RA] when you are ok, everything is good. When [you are] sick you count less.”

“They [friends] can go out, and do happy things, but if I go with them and stay on my feet the whole day, in the evening I am very tired. I will sit on the couch and sleep. It is not good life in this age. Then you ask yourself is it worth to live this kind of life at all? And you see… the years gone!”

“I was very energetic, I could work a lot to make extra money, but now I can’t work and for me it’s hard to accept help from my family. I don’t buy nicer clothes, expensive shoes to look better because now I don’t care at all. For me it’s not important now. I became more patient.”

Fear of loosing social status was observed in my respondents stories. My next respondent (43), who was diagnosed with RA five years ago and her disease history is relatively new, admits that she prefers that others do not know about her “weakness”. She told that this is the way that she resists her sickness:

“I don’t tell about it [RA] to everybody! I don’t want them to associate me with “weakness”. I know, if I tell them I will not be changed. You don’t want to admit to your friends that you are “different”, right? They tell me their own problems, then I am glad that I can help them and listen to them. It gives me kind of strengths. I don’t want to give people my problems until it is necessary!”

Similarly most of the respondents stressed that complaining about pain and complications from RA, is not what they should share with others. Almost all of them indicated that the people with whom they are very open about their sickness are their family members and very close friends. Some of them mentioned that only family members know about their RA. The comment of the next respondent (52) talks about how complaining about the disease is perceived by the RA sufferer:
“Often people with RA are self pity and keep on complaining how severe their pain is, how awful it is. Even though I am in pain, I don’t complain that much. But if they continue complaining, others will not accept it! Still you have to have interest in other people. If you can’t accept the fact that you can’t do everything any more, and people are complaining to others and don’t ask others how they are, I think they [others] quit!”

Fear of giving up her independence is shown when my respondent (45) mentioned that she still wants to do housekeeping by herself otherwise it will make her feel lower. Another respondent (52) recalled that she avoids watching how her home care person cleans her windows. She wants to do it by herself and is deeply hurt that she can’t do it any more and feels incomplete. A similar statement is in other respondent’s story:

“I don’t want home care person here… I want to do everything with my own hands myself; my mother helps me, she lives nearby, I do accept her help. I don’t want to give everything out of hands. Because then you will be depended.”

RA is not just a fact in my respondents’ life. Pain comes and goes in varying frequency and intensity. I studied how these “visits” affected my respondents’ perception of self. That’s why I asked all of them if they considered their health condition “being” sick or “having” sickness. All of them answered that they had sickness. The answers of my respondents complimented each other. The common idea is that they don’t want to associate their selves with sickness that came suddenly and disrupted their plans for the future. They fear that that their lives will be influenced by the disease. My respondents were showing that they actively were trying to ignore the pain and not to pay attention to RA and “keep it in the background”. Although their narratives say that pain has become part of their lives. One of them says that living with pain is her job, another respondent says that pain is something which grows inside her. There are several statements provided by my respondents:

“I am not ill and illness by itself. I am just person who has illness. I am no different from others who don’t have this illness. Someone has regular job and this is my job.”

“I have RA because I feel it every day… I have dry eyes, dry mouth, I have to drink water otherwise I will choke. It’s part of my life and also part of me, also I have to get used to it. I often have red eyes and people often ask me are you crying or so… It’s not my fault…but I have to I accept this fact. It’s mine and part of me. Unfortunately it’s me; it could be with someone else.”

“I am not sick person, I have sickness because I believe that it comes from outside and I don’t know when it will go away. When you have sickness it comes from outside and then grows inside you.”

“I have RA, it is just part of my life, but I am not completely consisted with RA.”
"I have sickness, it comes every day and sometimes when I have good days I don’t think that I am sick. I know in the background of my mind that I am sick, but I also don’t want to tell myself that I am sick. The more you say to yourself, the more you get sick."

“…It [RA] is part of me!”

“…It [RA] is illness that is inside me.”

Next to the aspects mentioned above, one more general pattern which respondents mentioned, is that when someone experiences many bad things in life s/he becomes wiser and starts appreciating life in different ways; S/he discovers things which were not visible before. From my respondents stories it was noticeable that life acquires different meaning and many values are redefined. In general terms life gets new meaning for them. This respondent (43) mentions that now she looks at life differently:

“I think you find many things not very important as other people do. You change your view! I think I did not always have optimistic view. Now it’s easier, but then [before RA] it was difficult… When I was younger, I was getting angry on simpler things, but now I am getting quieter. I am more balanced now. Now I am bit …“don’t care” type. So when I am feeling down I can put something that must do that moment aside and do it later when I am better. ”

Another respondent (45(D)) sees her life as a day and wants to enjoy life when she is pain free. She thinks that RA brings other problems and disappointments in life and makes you unhappy. But now she became a better mother:

“I do everything for my daughter, if she asks me anything to do. Before RA I was a strict mother. Now I have to live life as a day and don’t make a small thing as a problem.”

Similar to this statement, my next respondent (46) sees clear changes in her character:

“I am more open to others, more social. Before I lived on an island and now I am open to others. I became more careful towards myself: I plan more, I watch my food what I eat, I think more what and how to do. I became more organized.”

The narratives of my respondents showed uncertainty towards future. But some of them want to stay positive and believe in future. This can be connected with their course of treatment. The main concern will be lifted from them if the right medication will be selected for treatment. All of them know that RA is irreversible but it might be kept in remission at the same level. It is every one of my respondents wishes. The next respondent (37) says:
“The only fear I have is how I will in 10-20 years from now, but nobody can tell me about it. But I have to keep my body strong. If I go to the gym regularly it is good for my body and for my mind as well because you get healthier and with time if they [doctors] maintain this level as it is then I will be happy.”

The next respondent (52) who is disabled, is disappointed with life. Along with RA she has many other health problems. She had her breast amputated due to a cancer threat 2 years ago. She is still under stress that her other breast could also be affected:

“I am not emotional any more. I had RA for 20 years and when I got it first time they said that I could became disabled sitting in a wheelchair and that is my fear until now but… I am still walking and during years there are so many medications coming out that meantime you can stop it. Some people refuse to take medications, but I take this “poison” [refers to medication] and say that I can’t function without it. I need to function on my level. People, who have RA now and respond to medicines well, can often even work. Even though I can’t function with RA properly, but I would not been able to function if I would not get these medicines.”

Disappointment and hopes for future vary in my respondents’ statements.

The health care professionals take more realistic approach to the RA problem. They often see personality and character as very important aspects in RA management. In our interviews they mentioned that an important issue is to know how to live with RA. The rheumatologist said that:

“It is difficult to live with RA. It is about to adapt, make best of it, think positive, and try to get RA into remission. Be realistic and live healthy are important factors...”

The stories of my respondents described how their self is affected with RA. It is also believed that perception of self is vastly formed and influenced by reactions of others towards us. I will talk about it in the sub-paragraph how RA affected individuals relate to others. The reason why I divided these issues into separate paragraphs is that the latter talks about how RA affects my respondents’ social well-being.

### 4.1.4 Acceptance and denial

To understand my respondents’ psychological well-being, I decided to further study what cognitive mechanisms are triggered when person has to realize that s/he is not healthy any more and has to move from a status of being healthy to a status of being sick. The onset of a chronic health condition disorders a person’s knowledge and experience.
Therefore the sense of wholeness is disintegrated. After chronically ill people face disruption in their lives, they have to rethink and make necessary alterations in their lives. In this sub-paragraph I will show how the issue of acceptance and denial of chronic disease is described by the respondents of my study. I consider acceptance and denial as an active cognitive process which uses our inner resources.

When reconstructing the process of acceptance or denial, the narratives of my respondents showed that there is constant presence of disbelief and ignorance of their first diagnosis. The process of acceptance and denial takes a long time before the person finally acknowledges the fact of having the disease. From the narratives I found that acceptance and denial is an active process which goes through the stages. The relation between them varies and a person may move from one state to another and vice versa.

The commonality that I saw in the life stories was the fact that all my respondents described how they tried to ignore their pain and RA itself.

This informant (43(S)) has lived with RA for the last 22 years. Very characteristic in her story is that she constantly tried to ignore RA and accepted it only recently. Now when she can tolerate pain, she tries to ignore it, but when it becomes very severe she has to accept it:

“When I am working I am very good at ignoring it... I put much energy to ignore it. I have done much therapy and they [therapists] tried to teach me to accept the pain, give it some space. I try to do it, sometimes it works, the most of the time it doesn’t. I think I have fire, it is burning, aching and I can’t accept it.”

A long period of living with RA has taught the same respondent to realize why it is useful to accept pain. Nevertheless she refuses it due to its abnormal nature:

“They [doctors] tell you accept it [pain], because it will make your life easier for you. Maybe it is easier to live, but you have to accept something abnormal. Subconsciously you can’t accept it.”

Informants whose RA treatment with medications was not successful or whose body rejected medicines or had side effects may think that they were diagnosed with RA by mistake and that their current problem is temporary and will go away soon. This informant (45 (D)) said:

“I did not accept it [RA] for 2 years, I think because medication did not work. That time doctors did not give me right type of medication. That medication is for malaria, which is different type of thing. I did not believe them. Also, another side effect was that hair started falling down. That’s why, I thought maybe she gave me something not good for my body. Then stopped taking it. But pain was worse and worse and
after that I came here (the JBI) because it is a special place for RA, then she [rheumatologist] gave me prescribed drugs, after some time I felt relief. Then I got accepted my diagnosis.”

Intensity and duration of pain are important factors as to why it is accepted or rejected by my respondents. Most of them mentioned that their patience and endurance is compromised if it lasts longer. They accept it if it becomes intolerable. The next respondent (43) describes:

“And when it [strike of pain] happens I can’t do anything else. I don’t want to accept it, because I think, if I accept it, it becomes even worse. Sometimes I try to ignore it and go to the gym and continue working and I do that, but sometimes when it becomes worse I say OK, I have to accept it and now don’t do anything! Depending how strong pain is and also how long it is there! If it is there for several days, first few days are OK, but if it takes longer and longer it’s awful. Sometimes pain takes several weeks. And that’s really bad and I surrender!”

The mother of my respondent (43) has a severe form of RA. My respondent had symptoms that indicated that she might also have had RA. She knew that it was RA that caused her constant pain but was reluctant to visit a doctor and have it checked. After several years of bearing her pain she decided to have it tested. Her suspicions were found to be true:

“I knew that I had it, but never accept it, I liked to keep on fighting against it, but on the other hand I knew that it would happen one day. I never accept it. I was prepared to hear it but you are not happy to hear it, of course. Even now I don’t want to accept it. I try to ignore it… Yes, I do take doctor’s advice, but I don’t like to live into it! I deny it, sometimes I think maybe it is not true, sometimes yes it is true. Sometimes I want to keep on fighting so that I don’t give in because if you accept it, that’s it! It is going to be worse! I do recognize I have it but really accepting it NO! If I accept it then I will give in! I think so!”

For all my respondents it was not easy to talk about their feelings about the process by which its nature is abnormal and fight against it takes so much human energy from them. Nevertheless, my respondents gave explanations and described that cognitive process which makes them rationalize why they deny their sickness and what cognitive mechanisms will support their “journey” towards accepting it. My respondent (45(D)) when describing how she is coping with her immense health problem, said that when she feels worse she compares her health state with someone else’s state who is worse than her RA. This comparison helps her to feel better afterwards. She said:
“With this illness you can live, but some people can have worse problems like cancer. When you have RA you can live as long as other people but do you want so do so as long as everyone else! But I see a lot of people who are even more ill than me, they are in bad. Someone I know has MS and she was in a wheelchair some years ago. But now she can’t even stroke a cat and she has to stay in bad. If I meet someone like her, it makes me feel that I am OK!”

Another person (40) finds some positive side in her chronic hardship. She even admires herself for becoming stronger. She said:

“This disease meant for me, not because it is a punishment, but for something to learn. Maybe to show to other people how to deal with that. Every time I have hard time and life is getting awfully hard. When I manage it I feel better. I am surprised to myself wow, you have done it again? And then I get proud of myself.”

Similarly, another respondent (47) told me that before RA her life as of a professional pianist was dominated by self and she had to think only about her career. She was practicing for endless hours at the piano and had little time to look at life and socialize with others and enjoy smaller things. She explained that now she is disabled and doesn’t have a job, but helps other chronically diseased people by giving them advice through the internet. She said that she has became friendly and more social and started appreciating life more:

“I am helping to other people now… I have softened up! It’s very strange to say but I am the better person. If u are a musician, you always think about yourself: only me, me. I look other things different than 25 years ago. I get smaller; I have got more time to look at other smaller things around and enjoy. For example, trees are turning green…. Now it is a process I can look, and I am aware of. When I was healthy I did not have a clue about, did not notice many things.”

My respondents life stories showed me that those respondents who have had RA for a long time have more profound explanation why and how they should bear this burden. They believe that every person has their own problems and that they don’t need to go deeper in reasoning as to why it happened to them. One of my informants (43(S)) with long history of RA said:

“When you get older everybody has things in his past to carry with… For someone it’s a disease, for someone it’s a pain or something worse…”

Once the initial shock of diagnosis goes away and bodily pain becomes regular in my respondents’ lives, they start realizing that they have to apply some “strategies” to cope with the problem. These strategies come either consciously or subconsciously through the experience. One of my respondents named this as “an end of a mourning process”. She proceeded:
“I don’t want to be depressed. I let it [pain] come, I go along with my pain… it’s my enemy. I figure in my mind: OK, let it come and then I go along for this time. I say: you have my body for now for couple of hours! I am strong enough to face! I don’t want to surrender to that! It is my way of coping! It is like having and affair with a devil!”

My respondents cope with RA through different ways. If they have frequent pain and face the fact that it will last for a long time, they have to deal with it and get used to. Apparently, my respondents go through this process and come up with a solution by themselves. When I asked them how they see others’ place in the coping process, one of them (40) replied that it is a lonely journey and others are only invited into your problem. She know that:

“You need to come to the conclusion by yourself, I can do it myself. You must do it and then ask your friend or a husband to get a solution. Then it means that s/he is invited in that process… into your problem. It is how my mother wanted to help.”

Some of my respondents try to cope with their disease. Although there are factors which hinder the process of acceptance. Those factors could be easily related to the existing stigma which was traced in several cases. This is one of the reasons why acceptance of the disease is resisted. This respondent (43 S)) ponders:

“Long time I try to live my life as before but I have to do some adjustments… but it took time before I accepted it. Many people use special thinks like fork, knife etc. Adjusted to RA and similar people, but quite long time I did not want to even hear about it or see it at the beginning. Only later on maybe 5 years later I bought first thing that makes my life easier. For example I can’t use pen [grabs mine] this thin, it must be thick. There are more things you can try to use. It’s a challenge when you have disease to prove that you are normal. My challenge it to be as normal as possible. It’s almost impossible with the handicap…I see also people on the waiting room at the doctor with the same problems, but they are quite down with their problems, I don’t want to see them at all.”

From this statement one could say that resisting the acceptance of something negative and abnormal is a natural process and that is the reason why RA and pain are rejected by the body and mind. As all my respondents indicated it is a long process before one accepts abnormality as a really existed fact in his/her life. Some RA sufferers rationalize the whole process of acceptance. As my respondent (37) regretted:

“I can’t change about it; I have to enjoy my life now… it’s my view now. Of course I was emotional before, because everyone wants life that is normal, and there is health, a lot of money, pleasures… but soon I changed my view and I have to enjoy this life, no one will tell me what happens in future and I became more rational…
that’s my way to live now. I have my emotional time, but afterwards I want to change and stop… I am my own therapist… you know…"

She was trying to ignore and forget pain for long period, but now she gives the following meaning why she accepted the disease:

“Some people are 80 years old and don’t have so much pain in their life and some are 50 and sit in the wheelchair. I have to live my life as good as possible. I have a position “I will see”, I don’t want to think what will happen… I can’t stop it but also don’t want to think about. I don’t want to think about my future and I don’t have feelings.”

As few of my respondents mentioned, life challenge can be accepted. As one of them said you can even appreciate it afterwards. This respondent’s (40) life is spent in hospitals and she has undergone three pairs of joint replacement surgeries and several more will come soon. She said that everyone’s journey in life is different. We grow further and further with coming years, but if you are “off board” you learn more lessons. She accepted RA as part of her:

“Now I realize that life is so short and u have to enjoy and appreciate every moment. My life is not that the same as others have and that’s why I have to cherish every moment and even appreciate my body which has became deformed and crocked but don’t have to pay attention to it. Maybe it is the reason that I appreciate and even like my body now that several years ago.
I don’t like to think about the future. I don’t want to think…. It is worse, but I see when it comes. I know where I have been, where I am now and where it will be in 10 years. Joints I have are not good. Now I have second set of knees and hips and probably I will be in bad…I will wait and see!”

Every RA affected individual has their own ways of going through the acceptance process. They come up with their own conclusions. The next respondent (40), described her resistance to how she did not accept pain and RA. She mentioned that she has to live with her disease and accept it because she doesn’t have another option to fight it:

“When it takes long time you accept it in such a way that you say OK, now I take it easy. Although I never accept pain... but that moment I say to my pain: “leave me alone” and then I am close myself down.”

“Part of my feelings don’t accept it now, but rationally you get with your life, you adjust, you do things, so you have to live with it, when I go to the feelings’ part I get very sad. I don’t succeed in giving it a place. When I have pain, I still have to feel it. I don’t want it. I want it out.”

In the interview, health care professionals mentioned that accepting pain and the disease itself will ease life for a sufferer. It will help the patient to bring the disease into...
remission. To further study acceptance and denial from my patients, I wanted to know how they felt after they accepted their disease. For some of them it took years to accept, for some of them the process of moving from acceptance to denial and vise versa still continues, some of them still deny pain and RA. As my respondent (47) mentioned denial is an active mental process which takes too much from you including time, energy, efforts etc. it makes your life even worse in addition to your health condition. She compared the time lived in denial with tunnel vision. Bellow, this is how my respondent thinks:

“It took few years to believe it. It was me to deny accepting. Of course, life now it is easier… you don’t have to fight any more… this is only thing I was doing… I was fighting all the time. Now I have more time for myself… denial it is very active process, you don’t see the whole life, it is like tunnel vision, and you don’t see things on sides.”

4.2 RA effects on social well-being

4.2.1 Getting education

It was mentioned earlier that RA might bring changes in one’s life. I can assume that disruptive changes can be societal. Disruptions represent loss of opportunities in many areas and one of them can be getting education. The research was done in non-geriatric individuals with RA. The assumption was that at that age category RA affected individuals might not have completed their education level yet and RA might have disrupted their plans in this regard.

When analyzing my findings, I saw that most of my respondents are in their middle-age and at the time they were diagnosed with RA they had already completed their studies. Several of them did not fit into this pattern. There is one respondent (40) who has never fulfilled her dream to continue her education after completion of secondary school. At the time RA started, she was taking her final exams at secondary school. The physical and emotional shock was so strong that she never thought about moving to the next level of schooling. She mentioned:

“I was 16 and I had my exams. Then I did not have any concrete plan what specialty I wanted to obtain, but in general I was intending to continue… after RA everything was over at the age of 16. My only education is school of life. I have been only in hospitals, nursing homes and doctor’s offices…”
Another respondent (43(S)) was in the middle of her undergraduate studies. She found it extremely difficult to finish university. As she recalled, besides her workload at the university she had to deal with her worsened health and her emotional state. She became a linguist but never worked as a linguist. She said that she might retire earlier than other people. Then she will use her profession and will do editing of books or similar work at home.

The next respondent (45(D)) has a profession of a nurse and worked in an elderly care home. Her health deteriorated rapidly 5 years ago and she was not able to continue working as a nurse. She was concerned about her future employment and that’s why she started attending pharmacy school. After completion she will be able to work in a pharmacy shop. The life stories of my respondents showed that RA abruptly changes life plans to pursue further level of education.

In addition to my enquiry as to how RA affects my respondents life in terms of getting an education I got interested in how their educational level was affecting them in terms of experiencing the disease. That is why I asked my key-informants what their vision on this issue was. They mentioned that the level of their patient’s education affects the progress of the disease. There is a statement from the rheumatologist:

“When people have higher education level they read more about RA, they are more informed, have more realistic views what is possible and what is not possible. When [the level of] education is low then you have to explain more about medication and the seriousness of the disease. Sometimes they stop taking medication and you have to explain more and remind that it is really necessary to get adhered to the course to get the result. So more educated and intelligent you are, the outcome it better. …Sometimes they refuse to take medicines because of side effects and move to herbal supplements. I don’t believe herbal remedies! Sometimes I see people after they wasted their time and it is annoying.”

The next sub-paragraph will compliment the issues that arose in this sub-paragraph. There we will learn whether my respondents were able to apply their education in their career.

4.2.2 Employment

As I have mentioned in the first chapter, in the Netherlands, among RA affected people, withdrawal from the labor market is rather high and estimated 47.6% after a mean disease duration of 4.8 years. I wanted to explore what was behind those figures. The main idea was to find out what kind of emotions, feelings and thoughts were underlying their decisions to change their career plans. There are some findings from my research.
The table above shows what changes have happened in my respondent’s professional life since they started living with RA. Their narratives describe how RA affects their professional life and how it disrupts their future plans with regard to career. Among the ten respondents only two maintain their full-time jobs. But they are considering moving to part-time positions and changing the location of their employment.

The table shows that four of the respondents are presently disabled and are not able to continue regular professional life. Only one continues working as an accountant for her husband’s home business, but her working hours are flexible and are limited to few hours a week. As my respondents mentioned, because of RA some of them had problems in getting a job. Some have regretted that they had to quit their favored professions. Now they have to have less physically demanding jobs due to their health. Some respondents had to change their professions with the hope of adjusting their new career to their medical condition.

This respondent (43(S)) was diagnosed with RA at the age of 21 when she was in her last year at the university. She hardly managed to go through her final exams and after that was looking for a job. She said:

“After getting education I couldn’t get a job and mainly because of RA. I just heard that I was diagnosed with RA and probably because of that I was emotionally very insecure. I decided to apply for jobs through agencies. At that time I had many job interviews. I had to tell at the interview that I had a disease. I think I spoiled many interviews by saying them about my disease. So, in the end I got a job! I did not tell them about disease. At some point you realize that it does more bad to talk about your health... you feel obligation to talk about it but you have to make it as little [apparently not to talk in details about the disease] as possible.”

<table>
<thead>
<tr>
<th>Respondent’s age</th>
<th>Previous status</th>
<th>Current status</th>
</tr>
</thead>
<tbody>
<tr>
<td>37</td>
<td>Medical doctor (full-time)</td>
<td>Researcher (part-time)</td>
</tr>
<tr>
<td>40</td>
<td>School-girl</td>
<td>Disabled pensioner</td>
</tr>
<tr>
<td>42</td>
<td>Administrative worker (part-time)</td>
<td>Disabled pensioner</td>
</tr>
<tr>
<td>43</td>
<td>Business woman (full-time)</td>
<td>Business woman (full-time)</td>
</tr>
<tr>
<td>43 (S)</td>
<td>Police Department Administration (full-time)</td>
<td>Police Department Administration (part-time)</td>
</tr>
<tr>
<td>45</td>
<td>Dance performer</td>
<td>Journalist of performing arts (part-time)</td>
</tr>
<tr>
<td>45 (D)</td>
<td>Nurse (full-time)</td>
<td>Nurse (part-time)</td>
</tr>
<tr>
<td>46</td>
<td>Engineer (full-time)</td>
<td>Engineer (full-time)</td>
</tr>
<tr>
<td>47</td>
<td>Pianist</td>
<td>Disabled pensioner</td>
</tr>
<tr>
<td>52</td>
<td>Nurse (full-time)</td>
<td>Disabled pensioner</td>
</tr>
</tbody>
</table>
Over the years, the same respondent had several operations on her heals and had a wrist joint removed. Her left hand now is shorter and she is visible limping. She works in the police department and supervises groups working on criminal statistics. She likes her job although it is her biggest concern that she might have to retire soon and as a divorced mother has to think about how to support the family. She described how she manages pain in the office:

“At those times I am not at my best but I don’t want to give in that I am different than other people. In the office people don’t pay attention... they need work done, that’s it. You have to look very bad for too many days before they ask you what’s wrong with you [she laughs]. I think when I am in pain it shows itself. I have black spots under my eyes. There are people who notice and they try to make your work a bit easier at that moment. My intention consciously is not to let them know.”

Another respondent (45(D)) complained that she tries her best not to show her hardship to others in the office. Although they know about her medical condition, they do not always like when she needs day off when she is sick or need to visit a doctors. She said:

“If I need to go to the appointment to the doctor and want to live work early, I need to fill in the form...they [co-workers] say “again”? And you see their face, it is not nice! I always see their reaction.”

My male respondent (46) who is an engineer at a power plant faces the problem when he has to take a sick leave. He said that their work team is small and no one is happy when they have to replace him during overnight shifts. The youngest respondent (37) mentioned that due to her continuous pain she had to move from medical general practice to medical research and now works part-time during flexible hours. She said:

“When I was working as a doctor I was stressed, because I could not continue with my patients. Simplest thing as to measure blood pressure to my patients became very difficult... I had no power in my hands. I got frightened with thought that I could do mistake in my practice. So, decided to move to research and work part-time. I will stay in research. Now I have less pressure. I have to use only a computer [laughs].”

Due to RA, my respondents complained that their mobility is getting limited over time. That’s why keeping up with the demands of professional life is becoming very difficult. Most of them have moved to part-time positions and after that have had to quit professional life. Some of them choose to move into jobs which are not physically demanding. My respondents mentioned that the possibilities are becoming limited. Those people who had professional education, may stay in their field but have to explore other options if they want
to continue. For example, my respondent (47) was a professional pianist. She was
diagnosed with a severe form of RA when she was twenty five. Pain and inflammation in
her joints have deformed her fingers. She had to switch to become a music therapy teacher
for children. Ten years ago she had to stop working at all and now she uses a wheelchair.
Now she, along with another RA sufferer, runs a website designated especially for RA
patients. The website is very popular among arthritis sufferers.

It seems that through pain and disappointment RA affected individuals still manage to
stay active unless they are unable to do so. Another respondent (45) was a professional
dance performer. She told me that it was difficult to deal with the fact that she had to stop
dancing more than ten years ago. Dancing was her passion since her childhood. Now she
continues her career in journalism and writes articles and publication about dance, music
and other forms of performing arts. In her interview she mentioned that the emotional
burden from stopping dancing was even heavier than her physical hardship:

“I was doing dance for living, so it stopped. I can’t demonstrate properly any more,
yes it affected my career choice, I moved to teaching and forced me simpler
studies less physically intensive… I shifted to writing and in journalism. If I had not
have pain, I would have done more dancing, sure! But I had no choice.”

Another informant (40) mentioned that at the age of 16 when her RA started she
became disillusioned and never thought about acquiring a profession, because her life was
dominated by her ill health. RA dramatically changed her life and her aspirations had to be
abandoned in a very short time. She said:

“At the age of sixteen I was full of life and thought about future, but RA overwhelmed
me, I could not thing on anything else. At that time I was even worse, I did not know
how to manage pain and cope let alone my education and job. I was very young then.
Physical and emotional trauma was too much to handle. But now I am older and don’t
have many years left to live as before. Perception is changed. In my case, I know
where I was in live and where I go. I learned much from life… I had school of life
spent in hospitals and care home… But I could learn from something nicer than my ill
health.”

Social factors are described by my respondents as additional source of stress and
tiredness. This affects their health in a negative way indeed, but next to dealing with their ill
health they also have to think about how to support their family. This made one of my
respondent (45 (D)) study a new specialization. She attended a school to study pharmacy.
Her main hope was to work in a pharmacy shop part-time and get paid so that she could
support her daughter and an adopted son. On the day of our interview she seemed very
unhappy that she failed that exam and has to wait another three months to take an exam
again.
According to the present employment status, among the ten respondents only one person (43) was maintaining her position in a business company. During our interview she mentioned that she is considering quitting and finding a new job closer to her location. She was diagnosed with RA five years ago and so far she is able to control her pain more or less but it is becoming worse and has to rethink her career options.

Overall, from almost all my informants’ stories it seems that their professional life has changed and is compromised by pain. Difficulties in finding a job, extra efforts in maintaining employment, changes in specialization and acquiring a new but lower in grade position seems common among respondents. All these findings emerged from the interviews and confirmed assumptions existed in the field.

4.2.3 Creating family and marital relationships

I assumed that when people are diagnosed with RA during their reproductive age, their marriage and marital relations can be affected by it. Marriage and marital relations found very important to study. From my respondents’ stories I saw that relationships leading to marriage or separation were affected with RA in many ways. There can be many factors influencing marital relationships besides only RA. But I will try to show how my respondents narrated this issue in their stories. As it is shown in the second chapter in the profile section, among ten respondents, five are married including one person living with a partner and out of the five of the respondents there are two divorced and three single persons. When I closely analyzed my respondents’ stories, I found that three people remained single after having been diagnosed with RA. Two people got divorced after RA started in their lives.

One of the single respondents (47) said that when she was taken to the hospital the first time at the age of 25, her boyfriend left her. He never appeared. Since that time she never thought to start a relationship. Another respondent (40) was dating a boy and when she was diagnosed with RA, the boy stopped seeing her. Two of these respondents said that they were preoccupied by their shattered health and did not look for partners. Only the second respondent got married later on although she divorced after two years. When I asked why her marriage had ended, she said that although she married a man at her worst period of her disease and there was mutual affection, but she ended her marriage because her husband did not know what kind of disease was RA. She said:

“It [RA] ended my marriage. He [husband] was not careful. He did not want to know and read about RA. I did not see him to pick up a book or booklet and read about RA, [he] did not care about it. When I met him I was in my worse state, but we married. He
did not think RA as a problem. He saw me as a normal but on the other hand I am not!"

She confirmed me that it is a conflicting situation:

“Yes, I want to be seen as a normal, I would like to have a healthy body, but realistic is that I don’t have it. You want your husband to understand you and respect you. Say, if you want off day, you should have and he should respect it. I would like to be seen as normal and he wanted to see me as normal but on the other hand my illness was here and he did not respect that. For example when I could not go to the party, he could not understand why I was refusing. He did not read about RA and did not know what it was for me to have it.”

My respondent explained that RA was the real reason for her divorce, but she said that she sees her own fault in this as well. She referred to her marriage as her learning experience, but doesn’t blame herself in divorce:

“I know that it is my fault also. I was not honest with him by talking about my sickness, I set boundaries and when you do that people will stop go over it. If you don’t put up boundaries you can not complain afterwards that you walked over that boundary. I realized all this after divorce when I had more time to think about all this and it’s a shame that I did not talk with him, but what can you do? It’s life! You have to learn somewhere. I don’t blame myself.”

For this informant, thinking back at what had happened is also painful. I felt her feelings and her disappointment through her narrative. After her divorce she had two short term relationships but ended them because she looks at this in away that:

“Only understanding will not help to maintain marriage, you must be realistic to understand that we have problems.”

When I was searching for possible causes of ending relationships or marriages, I wanted to explore how my respondents were looking at facts inside marriage and the next case shows RA affected person has her own vision of facts. My respondent (43) ended her marriage after being together for five years. She explained:

“My ex-husband is a very nice and warm man, he was always caring and was always putting everything out of my hands and doing for me. It irritated me. He was caring too much and was doing things without asking me. This is what I could not tolerate!”

Next to her statement, she explained that this kind of action was only a reminder for her that she was a disabled person. She talked about feeling how painful it was for her that it was coming from such a close and adorable person. This is how she explained:
“When you have a disease you can’t influence on it. So you want to find the balance in life and continue as normal person... after this you have people around you who want to do things for you without asking for it. It is like they dictate you and want to take that part from you. Then you are nothing. You constantly have to fight that. It takes too much energy...

She told the story:

“...Last week my daughter had a show at school. We had to stand... but suddenly he brought a chair for me to sit. I did not ask for it. I could stand somehow... Yes, he is a gentleman to every woman but you can’t stop him, he is still overdoing it [after divorce]. He was always buying staff helpful for me: he was shopping things adjusted to my need without asking me. He looks at me as if I am a disabled. So it means that I am not a person, but someone with the problem.”

When looking at this story it can be mentioned that the vision of RA affected person can be different from those who are around them and as my other respondent said only love and understanding are not enough to maintain marriage. Being realistic in a relationship is more helpful.

There are stories of my respondents who are happily married and besides their pain and constant fatigue there is no influence of RA on their marriage or relationship. Partners of my respondents respect and understand their loved ones hardship. I tried to find out what keeps marriage happy and strong when one partner has RA. My respondent (40) with her failed marriage and relationships mentioned that it is not easy to start any new relationship now when you are disabled, but when you are already in marriage it is different because you already have foundation and you grow together. But if you have no basis it is not the same and it is difficult to start anything with your weak health.

4.2.4 Having children

RA occurrence in a reproductive age should have had certain influence on my respondents’ child-bearing. Among ten respondents one was a male who had three young children. My enquiry about child-bearing was directed to my female respondents. When analyzing the demographic data of my respondents I found that four of them did not have children and those of them with children had only one child. It is a known fact that RA affected females in their reproductive age can naturally have children. There is one issue which is advised to RA affected women. They have to cease taking medications against RA so that their blood is “cleaned” from those drugs. This period varies from one year to two years. Women are advised to get pregnant after that period. Several of them mentioned that this drug free period was an extremely difficult period in their lives, because they had to
endure severe pain and be constantly monitored for possible complications. All my respondents with children mentioned that period of pregnancy was pain and fatigue free. Many researches show that certain hormonal changes in a women’s body are to be mentioned as the reason for eliminating pain. After giving birth, all my respondents had to start taking their medications due to a very severe return of RA. They had to stop breastfeeding. None of my respondents’ breastfed.

The sharp and aggressive return of RA after childbirth is observed in all cases of my respondents. My respondent (40) longing for having a child had to rethink about pregnancy. She looked very sad when talking about it:

“I wanted children. I was off the contraceptive pill for ten months. I was trying to conceive. But at that time I saw an article in the newspaper about the link between RA and changes in bone density. Then I had secondary osteoporosis due to taking a strong medication and if I would give a birth, it would ruin me completely. Then I decided not to get pregnant.”

The youngest respondent (37) who has a one year son doubts that she will have another child because she has to cease taking medication first and the period without medication will be extremely difficult. My respondents were brave enough to go through their pregnancies. But after having one child none of them considered having another one. One of my respondents (43) mentioned:

“I have only one child. And I suppose RA is to blame. Pregnancy was alright, but the first 2 years of her life was very heavy for me. After normally I would not wish to have another child. I did not think about at all having another child”

As all my respondents mentioned, that after child-berth comes very painful time. This is another obstacle for not considering having another child. Another respondent (42) says:

“I have only one son, but we wanted more. I feel I am different from other parents of my son’s classmates. They all have three and more children…I could not get pregnant second time because of RA. In this sense I am different.”

One of my respondents (52) had her son via IVF. At that time she was single and was diagnosed with severe form of RA. She said that it was her conscious decision to have a child:

“I decided to conceive artificially from a donor. It was my choice. I was 35 and decided to have a child. I made decision. Even though I had RA, I did not mind! All people around me knew about it… That’s why I did not have second child because I
had to stay without medication long time. My health deteriorated after that but I don’t regret at all.”

RA affects the child-rearing process as well. My respondents mentioned that due to sharp pain they could not hold their newborn babies in their arms. One of my respondents (45 (D)) adopted a son from her relatives living abroad. At that time, five years ago she did not suffer from RA, but now she is afraid that she can not take proper care of him. she said that regretted that she adopted him. She said:

“If I have known that in two years would be living with RA, I would not have adopted him.”

These stories show that the nature of RA is a great drawback to starting a family and the ability to experience proper motherhood. These statements also show that despite many obstacles women with RA strive to cope with problems set by chronic illness.

4.2.5 Relating to others

Another main focus of this study is how RA affected individuals relate to others and how they perceive others. Others were categorized as people surrounding us including close family members, relatives, friends, co-workers and other people with whom we socialize. How chronic pain can affect performance of social roles and what emotions and thoughts prevail among RA affected people will be described in this sub-paragraph.

From the narratives, all my respondents answered that they became isolated from others. The reasons were linked with the natural course of the RA disease itself. It is pain, fatigue and other disturbing conditions which limit my respondents ability to socialize with their friends and even family members. This is what my respondent (43(S)) mentioned:

“I think it [RA] changed my previous relationships, because in the beginning you have friends with the same interests but when you get a disease some of them are going to react as if you are separated from them because you have problems. Maybe you want to be with them but you don’t want them to see you like disturbed and tired. After that you don’t want to socialize with them any more. I had friends who did sports, but when you can’t do sports with them… I think you are becoming more alone at that time and… you have to rethink how to deal with each other. With some people it’s going OK, but with some people not well.”

Social interactions with friends had become limited for my next respondent (45(D)) as well. She reasons that she tires quickly and is not able to keep up with the old rhythm of life. She said:
“I had good friends with whom I was going out … but now everybody gone. Yes! When I had pain and not feeling well I always said that I did not want to go out. They want to know how you are, but only for a while but after they don’t have interest.”

Another respondent (43) reasons that when she has pain she simply doesn’t want to see other people. The only thing she wishes during her pain period is to stay alone with nobody around her. Before RA she couldn’t even think about it. She was social and outgoing always in the center of the company.

From the story of the next respondent (42) I have learned that she, as a married woman with a 6 year old boy moved to another city where she did not have acquaintances. But her limited social interactions got even scarcer because she doesn’t want to start any new relationship. The reason was lack of energy and absence of interest in other people.

Based on the statements of my respondents, it was clear that when a certain pattern of relationship repeated over period of time then the process may will lead a person to a certain conclusion. It leads them to withdraw from social life. She said:

“We [friends] did things together, but at the end of the day I was the only one who had pain and problem. Next day the same and there comes time when you withdraw yourself!”

How others see my respondents’ health condition was found to be the most vulnerable issue in my respondents’ narratives. The statement of the respondent (45) echoes withdrawal among RA affected people. Feeling overprotected was another reason why my respondents decided to withdraw from social interactions with others. It was revealed that when my respondents feel excessive attention, most of them want to keep their distance from those people or social events. She mentioned:

“There are many people who really want to help me, advice me to find another doctor or tell me what was written in the newspaper about RA. It irritates me. When I was younger many people wanted to put me in a wheelchair before I even needed it. Now I have a car with automatic gear, but people were advising me to have it 20 years ago. At the moment I did not need it. The same with orthopedic shoes. I did not listen to them because I have my own doctor and he tells me what is best for me. If I had listened to all of them, I would write a book of advices [laughs]. So after all these you want more distance from them.”

Being overprotected by very close people provokes feelings which cause irritation and rejection in my respondents. As a consequence there was always conflict. In two my respondents’ lives it ended up with divorce. This is a story of my respondent (40):
“My husband was helping me a lot, saying: it is painful for you and I will help you. I was angry at that. I try to ignore my pain, look as normal as others are, and not to think about it, but when other person who loves you points it out and points that you can’t even cut vegetables and thinks you are disabled, which you already know, then it gets twice hard.”

Another respondent (43(S)) who also got divorced due to being overly cared for by her husband explains that sometimes you want to be as normal as others, not “that” person. Sometimes you want to be just a wife, sister, aunty, regular person not a disabled person with pain. If he gives help which you did not ask for it will irritate you. So, it is better if you are helped when you ask. Asking for a help is not easy for my respondents. This is the last thing they do. As one of them mentioned she is always late in asking for it. She does when it already caused pain to her body but nevertheless others must be cautious not to do it without permission. My respondent (40) who is severely disabled pointed out:

“Sometimes people just see you as a disease or a problem, or handicapped. If you love someone you just want to take care like you’d care about a child and protect from everything but we are grown up and we can do by ourselves and if we can’t it is our problem. I understand the loved ones have also hard times with us. They should have support as well. It doesn’t mean that I got rheumatoid arthritis alone. I have someone near me, s/he has to have support and care as well or everyone involved with a person who has disease should have support. You can’t cope with it alone.”

This statement should not be read only in the context of how RA affects social interaction. This is a more complex issue than can be seen at first glance. There is stigma enacted in most of the stories. Social relation is a two way process and others also contribute in forming this kind of vision. Often they forget how fragile the nature of the sufferer is. As mentioned above RA sufferer may start thinking that they are accepted not because of their personality but their disease. Only one respondent (40) mentioned that:

“It is hard to say! It’s my way of thinking. I know that my vision is distorted, not their vision. I can be difficult and I think I need to keep thinking not to lose point… but it is difficult.”

The research also revealed that my respondents release limited information about their disease to others. My respondents told that in general they don’t hide this information from others. They have to tell others about it. Although they think that people don’t need to know the whole disease story. Close family members usually know more than friends, colleagues or others. Several of my respondents did not easily inform others about their RA. This is how my respondent (45) described:
“It is going so long that it is boring to talk about it even with my partner! I don’t want to share it with others. There is nothing new to share…It hurts, and that’s it… People get bored! I don’t want to bore and burden them and when you start talking in depth what is that, they get really bored, so I say only that I have hip problem, that’s it. They ask me sometimes how I am, but I say I am OK. Only my close friends know this and they are concerned. I think they are more respectful about plans we make to do things together! I noticed they make it less physical… They try to accommodate me.”

Talking about the disease can become difficult for another reason. This is when my respondent may get feed-back from a person about how s/he looks and this is not always positive. Some people may say openly that s/he looks worse now than at a previous meeting. My male respondent (46) mentioned:

“Talking about my RA is not a secret, but I also I hide it easily. For example, if I don’t want a person to know about it I don’t tell it. When you have to stay at home many times then you have to tell about it to others that you are not healthy.”

My respondent sees more relief in communicating with people who have similar health problems. Here he describes again:

“I want to talk with others who also have similar problems, I want to share my experience with them… to get maybe some information which will be useful for me. That’s why I found the website [website for people who have different types of arthritis]. We share our problems, about medications, how they react on side effects, experiences and life in general. At the beginning you think that you are the only one. But later you realize that others have similar and even worse problems and it gives you strength to go on and be with others.”

The next respondent (42) doesn’t easily communicate her health problem with others. The reason is that she is afraid of getting negative views from others. She tells:

“Sometimes people say that I look worse. They say oh, your hands look so bad or worse. Now I am at a stage of my disease when you can see visible things of my RA and now I think that they know about it. I hate when they say that. It hurts me! I don’t understand why they say so.”

My next respondent (43), an energetic business lady who was diagnosed with RA 5 years ago, has the approach that sounds like “if you don’t know, you will not notice it”. Just a few people know about her RA. She prefers to keep it with herself and shares with husband and her siblings. The reason for doing so was her attitude not to be seen as a weak person. Disclosure for some people is not a real problem especially for those who have bodily changes and visible deformities. She came across the fact that sometimes co-workers may know about her health issue but easily forget about it:
“When I carry heavy box in the office and s/he knows that it will be good to help and s/he doesn’t do it, it is very annoying. It takes energy and time to explain again. For me it was difficult to admit to ask for a help. When you passed that moment when you let the person know about you health problem, you want that person to remember about it. So, I don’t explain every time. I understand that it is not easy for everybody to feel the same thing what you feel at that moment.”

The stories have shown that my respondents easily communicate the information about their health to their family members. As my respondent (37) mentioned it was difficult to accept her partner’s initiative to make house adjusted to her deteriorated health. The partner suggested installing an elevator in the house or moving a bedroom to the ground floor. My respondent has difficulties in climbing the stairs, but prefers not to do so unless she makes the decision herself. As it was mentioned above, my respondents want others to see them as normal people and don’t feel or act sorry for them. The informant (40) said:

“I don’t want them to feel sorry for me and ask all the time how are you and see me as a sick person. I want them to see me as a normal human being. I don’t want to let them know about my feelings and problems and see me in a wheelchair and that’s enough. I know how bad it is my situation but when it echoes back to me it will not help me!”

4.3 Interpreting living with rheumatoid arthritis

The present research also aimed at describing how RA affected individuals interpret their lives. Besides their life stories my respondents explain how their life is experienced with RA and simply what kind of comparisons they can make about it.

When explaining how her life looks now, my respondent (40) described it in a way that it was clear to see the points which I have already described in the previous paragraphs. She said:

“It [life] is intense. I have to live it careful to myself and to others, because you can lose friendships, you can also lose yourself in it. Intense! It affects many things in your life. It is like a mountain which you will never climb! You try hard and climb up but you slip away…you think you are near the pick, but slip away again… You don’t have grasp of life. It rules your life and body. Or it is nibbling your life like you eat cookie in small pieces… it eats just tiny bits and at the end you have nothing left.”

All of my respondents underlined limitations in their physical activities changing their lives dramatically. One of them (45) said that RA makes you less outgoing and it:
“Limits you in what you can do. I am referring back to physical thing and definitely it
doesn’t limit you mentally and intellectually but emotionally it does change you a lot.”

There are several expressions provided by my respondents when I asked them to describe
their pain and life in general terms:

“I live like a prisoner who has big metal balls on her feet. It is not a balloon, it’s a ball!
I walk with it every day; it’s there all the time.”

“…It’s like a heavy rainfall…it’s a long, heavy rainfall… I have no umbrella my
cloths also are dump, very wet, and you walk like that….all the time.”

“If I had to choose, I would not choose it. It hurts, it’s sad, it is not funny. You can
learn from it, but I could have learnt from other things. It’s my life, I have to accept it
and live it. I would not wish to anybody to have it.”

“…You are dying!”

There are expressions about how my respondents visualized their pain:

“It’s a pain you can’t cope with it. It is so heavy and intensive with redness, thickness,
and hot. You are getting very tired and you need more patience! It’s like fire,
everything is burning but you can’t extinguish.”

“When you move and you are stubbed by a sharp knife in your every joint and they
are so heavy that you can’t lift them anymore.”

“It’s like a tooth ache in my joints. Sometimes worse sometimes OK. It varies.”

“It is very tiring. It wears you down.”

“Sometimes I feel I am a dart board and arrows are directed to me. And I feel sharp
pain.”
5. Conclusion and Discussion

In this chapter I will answer the research questions stated in the fifth paragraph of the first chapter. The questions derived from the general objective of this study. The aim of the research was to explore and describe non-geriatric respondents’ own experiences and explanations on living with the chronic medical condition rheumatoid arthritis and especially with chronic pain which is one of the major symptoms of RA. In particular, I aimed at exploring how they respond to chronic pain, in other words how their psychological and social well-being was influenced by the experience of chronic pain. I will interpret the experiences of my respondents and I will try to link them with theoretical concepts which I have described in the third paragraph of the first chapter.

- Rheumatoid Arthritis effects on the body and psychological well-being

In order to understand the influence of RA in non-geriatric respondents’ psychological well-being, I decided to explore how their body, feelings and emotions and self image were affected by RA. I also studied possible cognitive mechanisms which may trigger when an RA affected individual realizes that s/he is not healthy any more and finds him/herself moving to a status of being sick. This process is characterized by a constant movement between denial and acceptance.

First of all I will start from how body is experienced by RA sufferers. Almost all respondents experience severe pain and bodily changes as a consequence of having RA. The common finding here is that respondents reported that their body became different; it has changed and feels heavy. Now they have no control over it. As one of the respondents explained the body let her down and she felt being cheated by her body. Most of the respondents said that they don’t like their body, it became unattractive, useless and it is even considered as being old. Some respondents developed bodily deformities; this restricts the sufferer from being physically active. Pain has become an integral part of the respondents' life. Chronic pain is experienced as an intrusive agent from outside; as an “unwelcome force producing great physical distress as well as moral and spiritual dilemmas” (Kleinman 1992:6). Overall, the body was perceived in negative terms.

One of the finding of this research showed that there is a clear pattern of feelings and emotions which is shared by the majority of the respondents. These feelings are generated by the constant and severe disturbance of the body caused by chronic pain which is typical symptom for this medical condition. Feelings caused by pain and fatigue are negative and almost all the participants feel being annoyed, frustrated, irritated, depressed, sad, emotional, angry, feeling down, disappointed. These feelings are evoked during ‘pain
periods’ but sometimes during remission as well. Many respondents also reported that their feelings were normalized after pain periods were over. These findings well accord with findings by Becker (1999) who discusses body and mind and refers chronic pain as major change agent in one’s disrupted life.

To understand the psychological well-being of RA affected individuals I focused on the relation between the self-image of the sufferer and the challenges caused by the onset and progress of RA in non-geriatric individuals. I suggested exploring how chronically ill individuals manage to reconcile their self identity with other social identities. In this regard I studied how the ‘self’ was perceived before the occurrence of RA and how it changed after the condition emerged itself in my respondents’ lives. The research studied experienced changes in character including new qualities of character, attitude towards life in general and the influence of the disease on the person’s self-image. The latter was studied through questioning whether informants considered themselves as “being” sick or “having” sickness.

The main finding when studying the perception of ‘self’ among RA respondents was the discrepancy between their answer to the general question whether they changed since the onset of RA on the one hand and the picture emerging from the content analysis of their narrated stories. The respondents persistently reported that their personality and character have not changed since the onset of RA, whereas their narratives revealed various transformations over the years.

In general, in their narratives I could see how they were reacting to life changes. There is evidence in the narratives that respondents’ character and personal qualities have changed and that new qualities are mentioned. When talking about the possible differences in their personality, they referred both to negative and positive changes. When pointing out on negative changes almost all of them mentioned that they would get easily angry, could be impatient to other people and be short tempered with them, they became tougher to the world, they are uncertain about their future and don’t have plans for future anymore. They want to live with one day and want to enjoy it as it permits them. It is also obvious that RA and related problems affect my respondents in perceiving time. Time acquired a different meaning over the course of the disease. It started going differently for them by running fast, they are more determined to live with today and enjoy it if possible. These findings confirm the research by Good (1992), who pointed out that as chronically ill person explains, time becomes distorted and its perception changes. During attacks and anxiety, the pain dominates inner time and breaks down the relationship between the self and the outer world. In addition, the stories contain statements which indicate that some of them
estimate their selves lower than it was perceived before RA occurrence, although they claimed that their self-worth and importance has not changed at all.

They also talked about clear positive changes in their character. None of them considered her/himself as sick and dependent. They mentioned that they were more patient to pain than before RA occurrence. Almost all of them felt that they were stronger as they could endure severe attacks of pain which may last for several days. Moreover, they felt that they had become more empathic and understanding towards others, and they did not take anything for granted anymore. These findings again confirmed research findings by Becker (1999) who argues that people attempt to create continuity after their lives are disrupted by the onset of chronic disease. Many respondents mentioned that they became open and more social. In general, life gets new meaning and values are redefined by looking at life in a different way. For instance, some see positive sides in their illness and try to cope with illness and adjust. There were statements indicating to fear to loose social status and to give up their independence. They referred that if they would loose their independence it would make them to “feel more incomplete”. None of them mentioned that they were dependent and insecure. This can be regarded as a strategy to resist the challenges of RA.

One more discrepancy was found between the straight YES/NO answer to my general question about perceived changes and the information derived from the analysis of their narratives where my respondents were referring to themselves as “having” sickness rather than “being sick”. If a respondent mentions as “having” sickness this implies that person does not identify him/herself with the sickness, considers it as an agent which comes from outside and therefore can not be controllable. On the other hand if the person considers him/herself as “being” sick there is “a fusion of self with sickness, of diagnosis with identity” (Estroff 1993:257). The content analysis showed that although all the respondents persistently mentioned that they “have” sickness their explanations indicated that RA is an integral inner part, it is inside them. The longer my respondents lived with RA the more likely it was that they would mention RA as a main part of their lives. This means that Estroff’s (1993) definition of chronicity and disability which arises when illness-relate identities overwhelm other roles and identities would be applied to my respondents’ experiences.

On the other hand, it was evident that my respondents were quite stubborn in repeating that they were the same despite changes in their character. In line with this, they emphasized that they were “having” sickness, were not depending on others, disliked overprotectedness and considered themselves as “normal”. They were well aware about the challenges they faced because of RA, it definitely brought dramatic changes into their
biographies, but at the end they maintained that their self identity did not seem to be affected negatively. In that sense the findings of this study contradict Charmaz (1983) where she argues that there is ‘loss of self’ when the person suffers from chronic disease. She regards ‘loss of self’ as the essence of chronicity. Charmaz mentions that there are four sources of suffering which affect the consciousness of a sufferer. These sources are: (1) leading restricted lives, (2) experiencing social isolation, (3) being discredited and (4) burdening others. But the findings of my research show that the first two sources of suffering do apply to my respondents, as for the last two sources it was evident that my respondents do not feel discredited or especially burdening to others and albeit acknowledging changes their narratives emphasize continuity of self rather than ‘loss of self’.

Estroff (1993: 259) describes four processes constituting the construction of chronicity and disability. These are “the temporal persistence of self and other perceived dysfunction; continual contact with powerful ‘others’ who diagnose and treat; gradual but forceful redefinition of identity by kin and close associates who observe, are affected by, or share debility; and accompanying loss of roles and identities that are other than illness-related”. From the findings of my research I would argue that these four processes do not seem to take place in my informants' lives. First of all onset of chronic illness is definitely experienced as a disruption, but the findings of the research show that the way my respondents are conceptualizing their self identity does not differ from ‘normal’ people and they don’t regard people who treat them as ‘powerful others’. Their life stories show that although they have more “ill-related roles” to perform, in the meantime they try to rationalize why their lives became restricted and why they became emotional, frustrated, angry etc. They used to mention that it was not him/her, it was RA to blame in their reactions. It means that my respondents feel the need to distance their self from the illness and that they thereby succeed in experiencing themselves as ‘normal’ despite going through the illness related physical and emotional burden.

This is in line with his research about the relationship between self-identity and social images of epilepsy by Reis (2001) whose findings also contradicted Estroff’s (1993) processes constituting the construction of chronicity. She showed that epilepsy may disrupt respondents’ lives but when they no longer suffer seizures their life normalizes albeit having epilepsy and having to take medication chronically.

It needs also to be mentioned that from the data I could not establish direct link between the severity of RA and the respondents’ self esteem. Based on the above arguments, I observed that my respondents manage to strictly separate their self and their illness. Therefore I came to the conclusion that the findings of this research do not accord
with the argument of Bury (1982), where he says that it is difficult to maintain a strict separation between illness and the self. In this research RA affected individuals do strictly separate self and illness.

To fully understand psychological well-being of the RA affected individuals I have also focused on studying on possibly existing cognitive processes taking place when a person moves from a status of a being healthy to a status of a being sick. After chronically ill people face disruption in their lives, it is thought that they have to “organize” these changes before they move on with their lives. Acceptance and denial of pain and RA itself are processes which take place when the respondent has to realize what happened and has to create a new meaning in his or her disrupted life. This is an active ongoing cognitive process which was observed in most of my respondent’s narratives. This finding of the research corresponds with the study by Becker (1999), who maintains that it is not possible to move on with life until the future is reorganized and redefined after the chronic illness. The mind has to adjust to the new requirements of the body. The process of adjustment is a difficult one but nevertheless necessary. Different respondents have different approach to the process of acceptance and denial. The respondents did explain that it is very difficult to accept RA in their lives. One of the respondent accepted RA after many years of denial and admitted that afterwards life became much easier because she was spending much energy on “fighting” against it and her vision to life was like tunnel vision and did not see good things on sides. Another respondent believed that denial was the best strategy to keep the disease away from her; she mentioned that by ignoring it she would keep it away from her life. Life stories of the respondents showed that they have different strategies to cope with their immense health problem. These coping strategies are individual for each of the respondent. While being sick they were helping others by giving them advice, comparing themselves to someone who is in a worse health condition, rationalizing the process by seeing even positive sides in it.

As mentioned, it was observed the respondents maintained a strict separation of their self and illness. They did not identify themselves with the disease. These respondents were also trying hard to maintain positive attitude towards life. It was revealed that those respondents who were recently diagnosed with RA and did not experience severe pains and those respondents whose pain and RA activity was controlled by the treatment had more optimistic vision to life. This finding is in accordance with the results of the research by Heide et al. (1994) which is about the relation between physical disability and psychological well-being in patients with RA with widely varying disease durations. The study results showed that psychological well-being observed higher in patients whose disease activity was controlled by the treatment and went into remission regardless its
duration. This finding once more confirms the research results by Reis (2001) who observed that life of respondents with epilepsy normalizes when they no longer suffer seizures. The finding of this research is also confirms the results of another research by Trehame G.J et al. (2005), which established the relation between optimism and lower physical suffering in early and intermediate RA.

Based on the above-mentioned findings, one important conclusion of this study therefore is that in spite of severe physical and emotional burden and negative and positive changes in the character, RA does not seem to deeply affect the psychological well-being of the respondents of this study. The respondents strictly divide their self and the challenges imposed by RA.

- **Rheumatoid Arthritis effects on social well-being**

  The second aim of this research was to study how the challenges caused by RA influence the social well-being of affected individuals. Analyzed data showed that RA brings changes and disruptions in various aspects of life. In order to understand these influences, I proposed to study issues such as getting education, employment, marital relationships, having children and relating to others. Doing research on non-geriatric respondents sets this study apart from studies on geriatric patients because there are major life changes happening in this age category which may coincide with the onset or progress of RA. In this regard the above-mentioned issues were important to study. Disruption may affect patients in such a way that further opportunities to pursue life plans can be hampered. My respondents mostly belonged to the category of middle-age. At the time of the onset of RA most of them already had their education completed in secondary schools, but several of the respondents who were studying in higher education institutions had experienced heavy physical and emotional burden when they have to deal with their workload and emotional shock caused by the onset of RA.

  This study also showed an obvious relation between employment rate and occurrence of RA among non-geriatric patients. The respondents in this age category are not close to their retirement period but the findings showed that there is a strong link between the disease and quality of the professional life of the respondents. All respondents spoke about facing problems to get jobs. They were afraid to fully inform their potential employees about their disease. Some of the respondents had to change jobs and even profession due to their deteriorated health. They looked for the opportunities to move to less physically demanding jobs. It was usual for them to think about early retirement as well. RA affected work relations at the job place by putting more emotional pressure to the respondents, for example, as several respondents mentioned they had to take frequent sick leaves, leave the job earlier than others when they had pain flares, or sometimes ask their
co-workers for a help due to certain physical limitations. This finding confirms the research results of Chorus (2001) and Verstappen (2005), which showed that the adjusted employment rates among RA affected individuals were lower and that disability rates were higher in patients with RA when compared with the general Dutch population. In addition, a substantial number of employed patients had to change their working conditions due to RA. Only a minority of work disabled RA patients was willing to return to the paid labor market.

Another important finding from the respondents’ stories is that having RA was related to broken relationships and broken marriages. It also influences women’s child-bearing ability. All the women reported that RA restricted them to have only one child or prevented them to have children at all. The main reason is the fact that the respondents had to stay medication free during a long period which was not easy to endure. While pregnancy progressed normally, after the child-birth the most of the respondents had very painful reverse of RA with severe complications. The effect of RA on child-rearing was also evident from the experiences of the respondents. RA related pain and introduced course of treatment soon after the child-birth prevented them to take good care of their newborn children, to breastfeed and in general to enjoy proper motherhood.

One more aspect in exploring social well-being was to study how RA affected people related to others and how they perceived their social roles. Further study of social relationships among the respondents revealed that RA and related problems may lead the person to isolate her/himself from others. They reported that social interactions became limited and over a certain period of time caused withdrawal of a RA sufferer from social life. Feeling oneself being overprotected found another reason why respondents withdraw from social interactions with others. Being overprotected by very close people provoked feelings of irritation and rejection leading to conflicts. This is in accordance with the results of the research about the relation of RA and support strategies for partners of RA patients by Jacoby (2003). Another conclusion of this study therefore is that in spite of vast improvements in medical and social sphere in the Netherlands, RA still negatively affects the social well-being of the respondents of this study.

The study showed that while the onset and progress of RA imposes severe physical and emotional burden on the sufferers, the respondents strictly divide and distance their ‘selves’ from the challenges imposed by RA, thereby they succeed in experiencing themselves as ‘normal’. Based on these findings, the important conclusion of this study therefore is that RA does not seem to deeply affect the psychological well-being of the respondents of this study. How RA affected individuals exercise control over their self and what strategies they ‘apply’ in that process will be the next anthropological study to further explore the relation of chronicity and self-identity.
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Annex

Research Instrument for individuals affected with RA

1. Basic information about respondents
   1. Name,
   2. Age
   3. Sex
   4. Marital Status: married/ widowed/ single/ separated/ divorced/ other
   5. Children
   6. Age of onset of RA
   7. Education
   8. Occupation: before and after onset of RA
   9. Location

2. Questions for Respondents

(I) The experience of chronic pain
   1. How often do you have pain in your body?
   2. If you were asked to measure your pain how would you rate it on the scale 0-10?
   3. How do you feel when you have pain? Would you please describe it?
   4. How do you talk when you have pain? Is it different from that when you don’t have pain?
   5. How do you behave when you have pain? Is it different from that when you don’t have pain? If yes, would you please bring any example?
   6. What do you do to manage pain?

(II) The experience of the body
   7. How do you perceive your body when pain comes?
   8. Is that different from that when you don’t have pain? If yes, how would you describe it?
   9. How do you relate to your body when you are in pain? Would you please describe it?
  10. How do you think about your body when you are in pain? Would you please describe it?
  11. How has your body changed? Does it become different? If yes, Could you explain it?
  12. How RA affected your physical activities and do you have to restrict yourself in daily routines?
13. What kind of assistance do you accept from your family members and health care professionals?

(III) The experience of chronic pain in relation to psychological well-being
14. How your mood is affected when you have to deal with pain? Does it change? If yes, could you specify?
15. How your mood is affected when you have to deal with the information about your chronic illness? Does it change? If yes, could you specify?
16. If you look back before you became affected with RA, how your emotions are different now?
17. Do you become emotional when you speculate about future? Would you tell how it affects you?
18. How your diagnosis has changed your character since onset of RA? If yes, in what extent?
19. Do you experience any fear, uncertainty, anxiety, and ambiguity when you think about your health? If yes, would you describe, if possible?
20. How do you perceive, did you become a different person since you have been diagnosed with RA?
21. How would you specify has anything changed in your personality? If yes, in what extent?
22. Have you acquired any new quality in your character? If yes, please specify. Any example?
23. What do you think why RA happened with you?
24. Have you ever “involved” your personality in reasoning why it happened with you at your age? If yes, how you would you explain?
25. How do you refer to your health condition (“being” sick or “have” sickness)?
26. What do you think what others (family members, friends, colleagues, strangers) think about your health condition?
27. What do you think what health professionals think about your health condition?

(IV) The experience of chronic pain in relation to social well-being
28. How easily you can disclose information about your chronic illness?
29. How openly you can communicate information on your chronic illness and associated pain to your family members, friends, colleagues, strangers?
30. Did RA alter or changed your previous relationships? If yes, in what extent?
31. Do you think that you are “different” from them? If yes, how you may explain?
32. Do you think people are treating you differently because of your RA, how, who, in what circumstances?
33. How did RA affect your social interactions with people? How different is it from your old pattern of social life?
34. Have you acquired a new life style? If yes, what does it look like?
35. How did RA affect your plans with regard to get education? If yes, could you describe?
36. How did RA affect your plans with regards to get employment? If yes, could you describe?
37. How did RA affect your plans with regards to maintain employment? If yes, could you describe?
38. How did RA affect your plans with regards to create family? If yes, could you describe?
39. How did RA affect your plans with regards to having children? If yes, could you describe?

(V) The interpretation of chronic pain and being chronically ill
40. If you were asked to compare your pain to anything else, what it would be like?
41. If you were asked to compare your life-style, what it would be like?
42. How would you interpret living with RA, what it is like? Would you please describe?

3. Questions for health care professionals

1. What is the role of biomedicine to cure or alleviate symptoms of RA?
2. What kind of burden is to live with chronic illness such as RA?
3. What does it mean for a health professional to deal with RA affected individuals?
4. How do different sexes experience RA from health professional’s perspective?
5. How do people in different age groups experience RA from health professional’s perspective?