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Abstract

Mauri Leino – The Influence of chronic diseases on household chores and leisure-time activities – with reference to low back pain, psoriasis, and rheumatoid arthiritis. University of Turku, Faculty of Medicine, Department of Public Health, University of Turku Doctoral Programme of Clinical Investigation. Annales Universitatis Turkuensis. Painosalama Oy, 2017.

Chronic diseases can negatively affect a patient's ability to perform household chores and leisure-time activities, which are an important part of everyday life. The aim of this thesis was to estimate from the patients' perspective how chronic diseases affect a patient's performance in household chores and leisure-time activities.

The chronic diseases covered in this study are low back pain (LBP), psoriasis, and rheumatoid arthritis (RA). All the patient samples were based on a systematic sampling of patients visiting the disease specific departmental clinics at Turku University Hospital. The participants either completed a questionnaire form or answered a telephone interview. The questions were comprised of both structured answering alternatives and qualitative parts where the participants were able to present their views, in their own words.

More than half of the patients with psoriasis reported difficulties in performing household chores because of the disease, with physically demanding tasks and those involving contact with water mentioned most often. Among the patients with RA, a disadvantage in household chores was perceived by over four-fifths; with the difficulties affecting a wide range of everyday household activities, and tasks related to house cleaning being mentioned most often. It had been necessary to organize assistance with household chores, because of their disease for three-quarters of the patients with LBP, a quarter of those with psoriasis, and for more than half of the RA patients. Four-fifths of the patients with LBP reported that they had had to reduce or completely give up at least one leisure-time activity because of the LBP, and this disadvantage was most pronounced among sporting activities. More than half of the patients with psoriasis had either reduced or completely given up at least one leisure-time activity because of the disease; those most often mentioned were swimming, ballgames, walking, and social activities. Among RA patients, a reduction or a giving up of leisure-time activities was reported by over three-quarters, with activities related to sport being the most affected.

Patients with chronic diseases perceive themselves as having considerable disadvantages in the activities of their everyday life, especially with the ordinary things such as performing household chores and leisure-time activities; both of which cover a significant proportion of people's time outside work. Thus, it is important to include such effects when measuring patients' quality of life. The findings of this study describe the magnitude of this burden of chronic diseases. The study also demonstrates the type of individual and social effects that improvements in treatment outcomes can be expected to produce.

Keywords: chronic diseases, household chores, leisure-time activities

Tiivistelmä

Mauri Leino – Kroonisten sairauksien aiheuttama haitta potilaan kotitoimiin ja vapaa-aikaan – käsitellen alaselkäkipua, psoriasista ja nivelreumaa. Turun yliopisto, Lääketieteellinen tiedekunta, Kansanterveystieteen oppiaine, Turun yliopiston kliininen tohtoriohjelma. Turun yliopiston julkaisuja. Painosalama Oy, 2017.

Krooniset sairaudet voivat haitata potilaan kykyä suoriutua kotitoimista ja vapaa-ajan aktiviteeteista. Väitöskirjatyön tarkoituksena on tutkia potilaan näkökulmasta, kuinka krooniset sairaudet vaikuttavat kotitoimista ja vapaa-ajan aktiviteeteista suoriutumiseen.

Tutkimuksen kroonisiksi sairauksiksi valikoituivat krooninen alaselkäkipu, psoriasis ja nivelreuma. Kaikki potilasaineistot perustuvat systemaattiseen otantaan Turun yliopistollisen keskussairaalan kunkin sairauden hoidosta vastaavan klinikan potilaista. Tutkimusaineistot kerättiin joko kyselylomakkeella tai puhelinhaastatteluna. Kysymykset sisälsivät strukturoituja vastausvaihtoehtoja ja laadullisia osia, joissa potilaat saivat ominsanoin kertoa vastauksensa.

Yli puolet psoriasis potilaista koki sairauden aiheuttavan haittaa kotitoimien tekemisessä. Useimmiten haittaa koettiin fyysisesti raskaammissa kotitoimissa ja toimissa, joissa iho joutuu kosketuksiin veden kanssa. Neljä viidestä nivelreumapotilaasta mainitsi sairauden aiheuttavan haittaa kotitoimien tekemisessä. Haittaa koettiin useissa toimissa, ja näistä kodin siivoaminen mainittiin useimmiten. Kolme neljäsosa alaselkäkipupotilaista, joka neljäs psoriasis potilaista ja yli puolet nivelreumapotilaista oli joutunut sairauden takia pyytämään apua kotitoimien tekemiseen. Alaselkäkipupotilaista neljä viidesosa oli joutunut vähentämään tai lopettamaan vähintään yhden vapaa-ajan aktiviteetin sairauden takia. Eniten mainitut aktiviteetit olivat urheiluharrastuksia. Yli puolet psoriasis potilaista oli joutunut vähentämään tai lopettamaan vähintään yhden vapaa-ajan aktiviteetin sairauden takia. Heillä eniten mainitut aktiviteetit olivat uinti, pallopelit, kävely ja erilaiset sosiaaliset harrasteet. Nivelreumapotilaista yli kolme neljäsosa oli joutunut vähentämään tai lopettamaan vähintään yhden vapaa-ajan aktiviteetin sairauden takia, ja näistä useimmiten mainittuja olivat urheiluharrastukset.

Krooniset sairaudet voivat aiheuttaa merkittävää haittaa potilaan jokapäiväisen elämän tavallisissa askareissa, kuten kotitoimissa ja vapaa-ajan aktiviteeteissa. Potilaan elämänlaatua mitattaessa on tärkeää ottaa huomioon tämä merkittävä haitta, sillä potilaan käyttämästä ajasta, työn lisäksi, kotitoimet ja vapaa-ajan aktiviteetit kattavat merkittävän osan. Tämän tutkimuksen tulokset kuvaavat kroonisten sairauksien aiheuttaman haitan laajuutta potilaan jokapäiväiseen elämään. Tästä tutkimuksesta saatavaa tietoa voidaan käyttää arvioitaessa potilaan hoidoista saatavia yksilöllisiä ja sosiaalisia hyötyjä.

Avainsanat: krooniset sairaudet, kotitoimet, vapaa-ajan aktiviteetit

Table of contents

Terminology and abbreviations

Chronic disease	A long standing disease, usually difficult to cure or non-curable.
Household chores	Housekeeping tasks that had to be carried out when living everyday life at home and its surroundings.
Leisure-time activities	Activities that are not related to paid work or household chores, which individuals perform during their free time.

DLQI	Dermatology life quality index
QOL	Quality of life
LBP	Low back pain
RA	Rheumatoid arthritis
PASI	Psoriasis area severity index
SF-36	Short form – 36
PsA	Psoriatic arthritis
WHO	World health organisation
HAQ	Health assessment questionnaire
LTPA	Leisure time physical activity
BSA	Body surface area
Kela	Social insurance institution of Finland
PDI	Psoriasis disability index
MACTAR	The McMaster Toronto arthritis patient preference disability questionnaire
OMERACT	The Committee on outcome measures in rheumatoid arthritis clinical trials
VAS	Visual analogue scale
NRS	Numeric rating scale
DAS	Disease activity score
min	Minutes
NS	Non-significant
h	Hours

List of original publications

This thesis is based on the following publications, which are referred to in the text by the Roman numerals I-IV.

I. Mattila K, Leino M, Kemppi C, Tuominen R. **Perceived disadvantages caused by low back pain.** Journal of Rehabilitation Medicine 2011;43(8):684-688.

II. Leino M, Mustonen A, Mattila K, Koulu L, Tuominen R. **Perceived impact of psoriasis on leisure-time activities.** European Journal of Dermatology 2014;24(2):224-228

III. Leino M, Mustonen A, Mattila K, Koulu L, Tuominen R. **Influence of psoriasis on household chores and time spent on skin care at home: A questionnaire study.** Dermatology and Therapy (Heidelb) 2015;5(2):107-116.

IV. Leino M, Tuominen S, Pirilä L, Tuominen R. **Effects of rheumatoid arthritis on household chores and leisure-time activities.** Rheumatology International 2015;35(11):1881-1888

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1. Introduction

Chronic diseases can affect patients’ lives in several ways. For some people the negative impact of the inability to work can be very devastating. The disease can prevent patients’ from performing their work duties completely or it can reduce the level of performance. Chronic disease can result in a financial burden for patients, as well as for their employers and society. In addition to the economic consequences, chronic disease can also have a negative effect on many everyday activities, such as performing various household chores and leisure-time activities. In addition, patients may also experience physical, psychological, emotional, and social constraints. Although being hindered from performing everyday activities may not always cause an economic burden, it can significantly decrease a patient’s perceived quality of life (QOL). Such influences of chronic diseases are not only limited to the patients themselves, but they can also have a secondary effect by creating a burden on the patient’s family members and friends. Family members, for instance, may need to take care of many household chores, which would otherwise be shared without the disease. Limitations in leisure-time and social activities do not affect only the patient, but can also have a have limiting effect on those individuals close to the patient.(1-7)

A whole array of household chores play a considerable role in our everyday life. Hindrance to performing them can start from getting out of bed, washing and dressing oneself, and preparing breakfast. Such difficulties may be faced by any patient, irrespective of age or sex. Throughout the day people need to perform tasks which can be affected by the limitations set by diseases. Running errands, cleaning the house, shopping, taking care of dishes or laundry, and just walking to the nearest shop may be tasks that are difficult or even impossible to perform because of the limitations caused by the disease. When a disease has a chronic nature, many patients learn to perform their necessary daily tasks with the help of assisting accessories or they learn to perform them with new techniques and sometimes at a lower pace and by allocating additional time to complete them. However, some patients occasionally need outside assistance, and others may need it constantly over a long period of time. Assistance may come from family members or friends. In such cases, it is mainly free of charge. However, the need to help a patient limits the helpers’ ability to enjoy their free time fully, because a certain amount of their free time is devoted to assistance duties. Sometimes paid assistance is required from outside sources, and this creates an additional economic burden on patients and their households. Patients may feel embarrassed to ask for help from other people, both from those who are close to them or more distant acquaintances; such embarrassment may produce additional emotional and psychological stress.(3,7-13)

Leisure-time is important for everyone, and leisure-time activities contribute to maintaining and improving our physical and mental status. Furthermore, through leisure-time activities people create and strengthen their social networks. For many people leisure-time is even more precious than e.g. work. Patients suffering from chronic disease are often forced to give up their job completely or work fewer hours than when they were free from the disease. In such cases, patients have increased leisure-time and the importance of being able to perform leisure-time activities becomes more evident. However, they may also have to give up some leisure-time activity that has had an important role in creating and maintaining social contacts. Therefore, the reduction in leisure-time activities together with fewer working hours can create an increased time of idleness, which can make patients feel redundant. A decrease in the ability to perform leisure-time activities due to chronic disease can form significant emotional, psychological, and social burdens on patients, and may reduce the ability to achieve and maintain physical fitness.(14-19)

Diseases with visible symptoms can create an emotional and psychological burden that affects a patient's social life. The stigma of visible symptoms can prevent patients from performing activities and they may prefer to hide any visible signs of the disease, or they may prefer to avoid activities requiring exposing themselves to others. Some symptoms are related to limitations of movements, or to performing movements that cause pain or other forms of discomfort. The extent of the burden may vary. Patients with the same or similar clinical disease status may experience it very differently. Moreover, the severity of the disease may vary over time, and this may cause variance in how same patients perceive the burden of the disease.(6,7,20-22)

When estimating the overall burden of a chronic disease, only considering the economic and productivity consequences may underestimate the impact of the disease. The influence of a chronic disease on everyday life because of the inability to perform household chores and leisure-time activities can have a significant role on a patient's QOL. In order to understand how strong the influence of a chronic disease is on patients' lives those impacts that are commonly studied i.e. economic and productivity loss, should be supplemented with the influence the disease has in the domain of everyday life.(1,2,10,23,24)

The number of studies focusing on the burden of these three selected chronic diseases on household chores and leisure-time activities has been limited, and those utilizing Finnish data almost non-existing.

2. Review of the literature

2.1 Definitions of the concepts used in this thesis

Quality of life (QOL) has been defined by the World Health Organisation (WHO) as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It has been said to include dimensions such as individuals' physical health, psychological state, level of independence, social relationships, environmental factors, and personal beliefs.(25) With chronic diseases, patients' ability to perform tasks related to everyday life is usually worse than without the disease. The WHO has defined disability as limitations to an individual's ability to act in a usual, customary, and personally desired way caused by one or more health conditions affecting physical or mental function (26).

Particularly in relation to RA a commonly used concept is fatigue, which has been said to be a subjective feeling of debilitating tiredness or weakness that interferes with physical and social activities. Fatigue has stated to differ from normal tiredness in that it is extreme, often unrelated to prior activities, and unresolving.(27) Belza and Mancuso (28,29) found fatigue to be significantly more pronounced in RA patients compared with healthy controls.

The health assessment questionnaire (HAQ) includes 20 commonly performed daily activities. The HAQ index measure is calculated based on patient's assessment of performance in each of the activities.(30) The HAQ is described in more detail later in the text.

The concept of household chores has comprised various activities, without concensus among researchers. The physical household tasks in the Pereira et al. study (31) included gardening, home repairs, home decorating, and chopping wood. Allaire et al. (32) discuss household work, which included cooking, after-meal cleanup, shopping and errands, taking care of others, general cleaning and laundry. In our study patient defined the activities included in the concept of household chores by themselves. Household productivity losses has been defined as housekeeping tasks that had to be carried out by formal (such as a paid housekeeper) or informal (family) caregivers, if the patient was unable to perform these tasks because of RA (8).

A reference dictionary for occupational therapy defines leisure activities as "intrinsically motivating activities for amusement, relaxation, spontaneous enjoyment, or selfexpression” (33). A similar description was given by Wikström et al. (34) who defined leisure activities as activities, active or passive, freely engaged in during one’s spare time, when all other necessary work was done. The significance of leisure activities may be different for different people, as the importance attached to activities has been regarded as subjective (31). Culturally relevant leisure activities can also be meaningful for the individual, and may promote health (31).

According to Caspersen et al. (35), physical activity can be defined as any bodily movement produced by skeletal muscles that results in energy expenditure. However, this definition is relatively inaccurate and open to debate. Physical activities that are not related to work could be referred to as leisure-time physical activities including sports, conditioning exercises, chores (for instance gardening and home repairs), and other related activities (35). In this definition, leisure-time physical activities also include several functions, which in other studies have been included in household chores. Exercise has been defined as a subset of physical activity that is structured, planned, and repetitive, and is performed with fitness in mind (35). On the other hand, exercising, walking (strolling), walking in woods, cycling, cross- country skiing, and dancing had been categorised as sports and conditioning exercises in a study by Reinseth et al. (36). Physical fitness has been defined as a set of attributes that people have or achieve that relates to the ability to perform physical activity (35).

However, the definitions of concepts used for household chores and leisure-time activities in the literature are ambiguous. In some cases, the concepts used are more detailed in order to describe its content more accurately, such as “leisure time physical activity” abbreviated as LTPA. In the original articles, which this thesis is based on, the concepts household chores and leisure-time activities have been used systematically. These concepts are also used in this thesis, and if the articles referred to have used some other definitions and terminology, this is mentioned separately.

In the literature search for this review the used terms and concept were “household chores” and “leisure-time activities” and several others with similar or close to similar meaning. Such search terms and concepts were defined by the author. Typical other terms and concepts included e.g. the following: household activities, household work, homework, housework, daily activities, everyday life activities, leisure activities, leisure time physical activities, exercise, and hobbies. Systematic search of these terms and concepts produced many articles with main focus on quality of life, but also covering some elements of household chores and leisure-time activities. These were also included to the extent that was deemed relevant for this study. The literature search was performed in PubMed and Medline databases.

2.2 Low back pain

Overall, little research has been conducted on the relationship between low back pain (LBP) and patients performing household chores or leisure-time activities. It has been estimated that LBP affects up to 84% of people at some point in their life (37,38) and that the incidence and prevalence of LBP are fairly similar all over the world (39). In Finland, the prevalence of LBP has increased during the last decade (40). The highest incidence has been reported among those aged 25-64 years (41). Although back pain seems to be equally common in men and women, back and spine impairments have been shown to be more common in women than in men (42). The two most important symptoms of LBP are pain and functional disability (39,43,44). Very few chronic low back pain patients suffer from an inflammatory disease (44). After an initial episode most of the people with LBP suffer relapses of pain. Acute LBP is defined as pain localized below the costal margin (the line of the twelfth rib) and above the inferior gluteal folds, sometimes accompanied by radiating pain, for up to 6 weeks (44,45). Pain that continues for 6-12 weeks is defined as subacute, with longer periods of pain described as chronic (44,45). For most LBP patients the condition has been defined as non-specific LBP (41,44), meaning there is no clear specific cause for their LBP symptoms, for example malignancy, fracture or infection. Most LBP studies have concentrated on non-specific LBP, as it is extremely common. Consequently, in this thesis when referring to LBP, it means non-specific LBP, unless stated otherwise. The prevalence of chronic LBP has been estimated to be approximately 23%, with about 10% causing the sufferers a certain amount of disability to some extent (37). However, scientific evidence on this matter is scarce (38).

LBP is considered to be one of the major causes of musculoskeletal disability (42,43) and a common reason for using health care services (42,43,46). LBP has been stated to have a considerable negative effect on patients' QOL (1,47). According to a Norwegian study (48) among low back pain patients, the 5 most frequently listed areas affecting QOL were pain, sleep, stiffness, socialising, and housework.

The psychological aspect has been shown to have an important role in patients with LBP. Risk factors associated with LBP have been e.g. age, female gender, and smoking. (42,49) However, Woolf (41) argued that LBP affects more men. The prevalence of chronic LBP has also been suggested as being determined by heredity genetic factors, which are estimated to explain 32% (50). In addition to the financial losses to society and patients, LBP also has a major impact on various aspects of patients' everyday lives. To measure the pain and disability of LBP a wide range of instruments have been developed (51) and despite the clinical and economic importance of chronic LBP, the overall burden of the disease has not been well documented (52), and studies concerning the burden in household chores and leisure-time activities is almost non-existing. Based on the above information, it has been stated that LBP is an elusive condition affected by a host of genetic, physical, psychological, environmental, cultural, and societal factors (37).

2.2.1 The effect of LBP on household chores

The role of household chores in coping with everyday life is considerable. Despite pain, everyday life requires a certain amount of physical activity and performing at least some necessary household chores. In the Turk et al. study (53), household chores were more important to the patients than hobbies, but less important than other physical activities. In a Swedish study (47) with 302 LBP patients over 18 years of age, 61% of the patients reported that during the previous 3 months they were unable to perform household activities. On average, the patients were unable to perform household activities on more than half of the days (52 out of 90), and on average, the inability lasted 3.3 hours during those days. In a Finnish study (54), one-third of the LBP patients reported that they had been obliged to reduce their everyday duties. When this rate was compared with a corresponding rate in subjects without LBP, the estimated proportion of the limitations attributable to LBP was 16% (54). It is worth noticing that also in other studies a proportion of the reduced ability to perform everyday tasks may be due to concomitant conditions or diseases, even though the study has been conducted among LBP patients.

An American study (55) with 1002 moderately to severely disabled women aged 65 years or older, showed that women with severe back pain were 3 to 4 times more likely than other women to have considerable difficulty with light housework or shopping; they were also about twice as likely as other women to report a great deal of difficulty when climbing stairs, walking two to three blocks, lifting 10 pounds, and activities of daily living (bathing, dressing, eating, transferring from bed to chair, and using toilet). However, the authors did not find associations between back pain and being unable to perform any of the daily activities studied (55). According to the author’s knowledge there are no studies reporting differences between genders as regards the effect of LBP on household chores.

The burden seems to be particularly pronounced in certain patient groups. In a French study (56), with 1072 patients from the active work force with chronic LBP, 80% reported that LBP impaired their ability to perform the activities of daily living, such as toileting, driving, and doing household chores. Twenty-one per cent of the patients were considering cancelling plans made with their family and 23% reported a negative impact on their ability to care for children or grandchildren because of LBP. Conversely, 29% of the patients reported that manual tasks about the house, home improvement activities, or gardening were the cause of the latest exacerbation of LBP.(56)

Forty-seven per-cent of the patients treated for LBP reported having spent less time on housekeeping, shopping, doing odd jobs and childcare during the week prior to the study (57). Every tenth participant said they had reduced these activities by over 20 hours during the week prior to the study (57), which is parallel to findings in a Swedish study (47). Low back pain also has been reported to be associated with disability in the activities of bathing, doing the laundry, performing heavy household chores, cutting toenails, shopping, carrying a shopping bag (58), getting dressed, climbing stairs, walking and bending/kneeling (7).

Sometimes LBP can have an effect on performing household chores to such an extent that patients have to ask for help from relatives or other helpers to manage their household chores. In a Swedish study mentioned earlier (47), 43% reported that during the previous 3 months they received help from family and friends in performing household work. In another study, housekeeping tasks were taken over by others for 35% of the patients treated for LBP (57).

2.2.2 The effect of LBP on leisure-time activities

Among chronic pain patients both physical activities and hobbies has been stated to play a large role in patients' lives (53). For most of us leisure-time activities form an important part of a meaningful life and people wish to participate in these activities despite the pain. Woolf et al. (41) hypothesized in their review study that episodes and fear of recurrence of LBP may affect strenuous activities and leisure pursuits among LBP patients.

According to Smeets et al. (14), chronic LBP patients had a significantly lower level of measured aerobic fitness compared with healthy controls matched for age, gender, and level of sport activity during the preceding 6 months. The authors found that this difference was not significantly associated with pain, the level and duration of the disability, a fear of injury, or the activity level during work, household tasks and leisure time. The authors suggested that the intensity, duration, and frequency of the activities performed by the patients were much lower than before the LBP started or they already had a lower level of aerobic fitness level before developing chronic LBP. They also found that male patients with LBP experienced deterioration in aerobic fitness more often than female patients.(14) It may be that a lower level of aerobic fitness may further promote the experience of disadvantage among LBP patients and predispose them to other disabilities. On the other hand, regular physical activities can be expected to improve aerobic fitness.

In a relatively large French study (56), nearly one-third of the patients refrained from participating in sporting activities because of their LBP. In a Finnish study (54), 39% of the patients with undefined LBP had to limit their leisure-time activities permanently because of the disease, and the estimated proportion of the limitation attributable to LBP was 17%. Ten to fifteen percent of the children and adolescents between 10 to 18 years of age with LBP had reduced or stopped their sports activities because of LBP (59,60). The percentages in these studies may seem relatively small. These study populations differs significantly from adult populations as the duration and probability of the severity of the condition differs.

A study with chronic LBP patients in two rehabilitation centres showed a lower activity pattern compared with healthy controls, especially during the evening, when measured over a 24-hours period with an ambulant monitoring system measuring physical activities. The finding was reflected in a lower walking step frequency during the day and evening, more time lying down during the day, a lower physical activity level, and less standing time and more lying down time during the evening. The authors suggested that this might indicate that the patients need all their capacity to perform the tasks imposed during the day and as a consequence have less capacity during their leisure time, particularly in the evening. This suggested the existence of an imbalance between the patient's physical capacity and the imposed environmental load.(61)

There has been a considerable amount of research conducted on the relationship between physical and leisure-time activities and household chores on the development of LBP. In the French study (56) mentioned earlier, one fourth of the patients ascribed their latest exacerbation to a sporting activity, and four fifths had had to stop this activity. LBP may have a negative effect on performing household chores or leisure-time activities, but on the other hand performing household chores and leisure-time activities may also predispose LBP exacerbation. However, a review study by Bakker et al. (9) showed that there is strong evidence that sport and physical exercises is not associated with the development of LBP. The authors also reported that in leisure-time activities the risk factors for LBP decreased with more intensive gardening/yard work (9). In addition, Eriksen et al. (62) found an increased risk for LBP in subjects that exercised less than once a week. According to a more recent study by Pinto et al. (63), self-reported moderate-to-vigorous LTPA predicted less pain and disability over a 12-month period in a group of chronic and persistent LBP patients, compared with the sedentary or light LTPA groups. On the other hand, the moderate-to-vigorous group had less severe pain and disability than the other two groups also at the beginning of the 12-month study period. However, after adjusting for other baseline characteristics, those people engaged in moderate-to-vigorous LTPA showed statistically significant reductions in pain and disability compared with the sedentary group.(63) Similar trend was also reported in a study comprising young adults with LBP (64). Two Australian case-control analyses (50,65) with twin pairs showed that moderate physical activities such as jogging, cycling, swimming, aerobics, tennis and golf was not significantly associated with LBP, but the daily amount of time spent sitting was positively associated with chronic LBP.

In contrast, one study hypothesized that eliminating the physical load can theoretically reduce the burden of LBP by 13-18% (66). In the Australian studies (50,65), the higher prevalence of chronic LBP was associated with light walking exercises and vigorous gardening or heavy work around the house and yard, but in their multivariate model, only time spent in vigorous gardening or heavy work around the house or yard was significantly associated with chronic LBP. According to a population-based longitudinal cohort study with 1836 subjects, who reported persistent back pain, regular LTPA seemed to improve recovery from persistent back pain among the women, but not among the men (67). Bakker et al. (9) concluded in their review study that according to the literature there was conflicting evidence for leisure-time activities being a risk factor for LBP.

The literature review by Ribaud et al. (15) reported that globally, physical activities like swimming, walking and cycling, practiced with moderate-intensity, help to maintain fitness and control pain. Inconsistent results were found in the recommendations for avoiding sports according to the nature of physical activity. Sport activities, other than ballgames, were suggested to be easily to resume or take up. Tennis, horse riding, martial arts, gymnastics, golf, and running were mentioned because, according to the authors, these may be performed with lower intensity or at a lower competitive level. The authors concluded that moderate but regular physical activity helped to improve fitness and did not increase the risk of acute pain in chronic LBP patients.(15) It may be that LBP patients are forced to reduce or modify their leisure-time physical activities, but in many cases they may be able to continue them with less intensity, instead of being forced to give them up completely.

It seems that there has been a limited amount of research conducted on the effects of LBP on performing household chores and leisure-time activities. The scientific work conducted has tended to concentrated more on studying the influence household chores and leisure-time activities may have as possible causes of LBP (9,15,62,63,65-67). However, the findings are inconsistent. Both household chores and leisure-time activities may increase LBP in some cases, but they can also be helpful in the control and prevention of pain, and thus improve a patient's ability to function. It has been recommended that for each individual it is important to find safe and effective forms and prescribed amounts of physical activities to be included in physical activity guidelines or in the promotion of physical activity aimed at preventing LBP (65).

Together with the physical disadvantages, LBP can cause considerable social, emotional, and psychological harm. In a relatively small qualitative study from France

(68), participants with chronic LBP often reported a negative self-perception in social interactions, mentioning as a cause the shame and frustration they felt regarding their difficulties to perform the activities of daily living. They had often felt misunderstood and unsupported, partly due to the absence of visible signs of the condition. Participants reported that they suffered from the negative collective image attached to LBP. For some patients in the study, LBP resulted in a significant loss of social identity with a perceived impossibility of performing one's social role at home and at work. In contrast, family and friends were sometimes a support and helped in pain management.(68) In one study 58% reported significant negative effects on their emotional life, 46% on their sexual activity, and three quarters of the patients reported a negative psychological impact (56).

Based on this literature review, non-specific LBP is common all over the world. There is good consensus in the literature that LBP negatively affects the performance of household chores and leisure-time activities, even though the number of studies remain small. The physical disadvantage in performing household chores and leisure-time activities could be a social, emotional, and/or psychological burden to the patient, and this may decrease their QOL. In the LBP literature, the patients' perspective is infrequently taken into account, as is the burden of LBP in those life domains considered important in everyday life by the patient.

2.3 Psoriasis

Psoriasis is a chronic inflammatory disease with mainly skin manifestations (69). Recently, the World Health Organisation (WHO) listed psoriasis as a serious non-communicable disease (NCD), in the same group of diseases as strokes, heart attacks, diabetes, and pulmonary diseases, which indicates the significance of psoriasis (2). Being one of the most common chronic skin disorders its estimated prevalence in European countries varies between 0.5 and 8.5% (70-72). Most studies in Europe and the U.S. have reported a prevalence of between 0.5% and 4.6% (70,71,73,74), with men and women being equally affected (74). In a large cross-sectional study in Finland (75), the prevalence of psoriasis was estimated to be around 2.6%. Although psoriasis may occur at any age, the majority of patients report an onset before the age of 40 years (76). Bimodal distribution has also been suggested with a second peak of onset at around 50 to 59 years (70,76).

There is evidence of genetic inheritance, and several genes have been associated with psoriasis (69). However, the primary trigger of the disease has remained unclear (69,77). Chronic plaque psoriasis or psoriasis vulgaris is the most common form of the disease, affecting 80-90% of patients (69,73,77). Other types of psoriasis include inverse psoriasis, guttate psoriasis, generalized pustular psoriasis, pustular psoriasis of palms and soles and erythroderma (77). The most frequent psoriasis symptoms reported by psoriasis patients are scaling, itching and erythema (10). Around 5–35% of patients with psoriasis also have psoriatic arthritis (PsA) (77-83). Patients with arthritis have exhibited a greater impairment of QOL, a longer duration of the disease, and a greater self-reported disease severity for psoriasis than non-arthritis patients (83).

Severe psoriasis has been associated with several comorbidities such as cardiovascular diseases, metabolic syndrome, and depression (76,84-87). Furthermore, patients with severe psoriasis have been shown to have a higher risk of mortality than age-matched patients without the disease (88,89). The impact of psoriasis on a patient’s QOL has been shown to be similar to that of other major medical diseases (90).

A variety of methods to measure the severity of psoriasis have been developed (76). The most commonly used methods include measure of the magnitude and severity of the clinical symptoms of the skin e.g. using the psoriasis area and severity index (PASI) and / or assessing the affected body surface area (BSA). PASI values range from 0 to 72, with higher values indicating a greater coverage of the disease and severity.(91) PASI values are based on an assessment of the patient’s lesions by a health care professional (92). PASI is calculated from values of four body areas (upper limbs, head, trunk and lower limbs), which are assessed for the proportion of skin affected (from 0–6) and the severity of the lesions (from 0–4) (92,93). Patients have been considered to have a severe disease if the PASI values are either above 10 (94) or in some sources above 20 (93). PASI is the most widely used measure of severity in the research as well as in clinical setting. Studies have indicated an inverse relationship between QOL and severity of psoriasis.(20)

The effects of psoriasis on the QOL have been measured with many types of questionnaires, including generic instruments, such as a short form-36 (SF-36), and dermatology specific instruments such as a Skindex, and a Dermatology Life Quality Index (DLQI) (76,92,95,96). The latter has been commonly used to determine the QOL of patients with skin disorders, and the instrument is considered to be well validated, however, it has exhibited some defects such as minimal clinical difference (96,97). DLQI is also the measure used by the current care guidelines in Finland and the Social Insurance Institution of Finland (Kela) to determine the effect that psoriasis has on the QOL (98). There are also psoriasis specific QOL instruments such as the Psoriasis Disability Index (PDI) (96). Although the use of a generic instruments allows the impact of psoriasis on QOL to be compared with other diseases, more specific questionnaires may provide more accurate and specific measures of psoriasis. DLQI is the most commonly used dermatology specific measure, in which values range from 0 (QOL not affected at all) to 30 (QOL severely affected) (97). Patients with a DLQI above 10 may be considered to have a severe disease (94).

According to large studies from the US and Europe, psoriasis has a significant negative impact on patients' QOL (10,20). In a study by Delfino et al. (99), physical comfort, social comfort, and emotional health were the areas of life most affected by psoriasis. Patients diagnosed with psoriasis have reported that psoriasis was a problem or a considerable problem in everyday life for 40% - 77% of the patients (10,100). In a US study (101) based on the National Psoriasis Foundation Patient-Membership Survey, 79% of the 502 respondents to the telephone survey, who had severe psoriasis, reported that psoriasis had a negative impact on their lives, and 40% felt frustrated with the ineffectiveness of their current therapies. The negative impacts included on average a disruption to their daily activities for 10% of the time each month. Thirty one percent reported that they had suffered from some degree of financial distress resulting from their psoriasis. In the same study, the most frequent symptoms experienced by the 17 425 mail-survey respondents were scaling (94%), itching (79%), and skin redness (71%).(101) These three symptoms are also those most frequently reported in Europe (10).

Psoriasis patients have reported a reduction in their physical and mental functioning comparable to that seen in patients with cancer, arthritis, hypertension, heart disease, diabetes, and depression. The authors found that the lesional severity of psoriasis was clearly associated with the patient's QOL, but it did not account for all or even most of the variability in their QOL. The study discusses the fact that a wide range of physical, psychological, and social aspect of the disease contribute uniquely to the sufferers QOL.(90)

In an Italian study (102) with 936 hospitalized patients, with mainly moderate psoriasis, the QOL of the group of 65 years or older was significantly more impaired, regardless of the severity of the psoriasis, than that of those under 65 years old; the psychological distress was also higher in older patients. In particular, older women suffering from anxiety or depression had the greatest impairment in their QOL. Quality of life was consistently more impaired in women than in men. According to the authors, similar levels of clinical severity in psoriasis may be associated with different levels of QOL and the psychological distress of patients.(102) In that Italian study patients were hospitalized, indicating that they had severe onset of psoriasis, which probably had an influence on the results. On the other hand, Gupta et al. (87) found that psoriasis patients with a wide range of disease severity, there were no age or gender differences in the severity of psoriasis, and, in contrast, patients under 46 years of age reported more impact on their QOL than older patients. A review study by de Korte et al. (16) summarized that among psoriasis patients a higher age was associated with slightly lower levels of physical functioning, slightly higher levels of psychological functioning, and overall QOL. According to their review, gender and QOL were found to be unrelated (16).

Moreover, in a study with 6 497 Nordic patients with psoriasis (103), the older and married participants reported less impairment to their QOL than younger participants and those living alone. In that study, the self-reported severity emerged as the most significant predictor of psoriasis-related QOL, although, other factors including age, country, marital status, and employment status were also found to play a minor role. PASI was not a significant predictor of QOL in that study even though the PASI scores did correlate with the self-reported severity.(103) In a large US study (101) although 39% of the mail-survey respondents had self-reported to have 10% or more of their body covered with psoriasis, which therefore would be classified as severe, only 17% rated their disease as severe. The burden of the disease experienced by the patient could be different from that evaluated by using clinical measures. However, according to the above mentioned literature the findings of the relationships between QOL, age and gender are inconsistent

In an 11-year prospective study by Unaeze et al. (21), with 484 psoriasis patients, the impact of psoriasis on the participants' QOL decreased over time. The impact on most social aspects of their QOL remained stable according to the study, but concerns related to physical appearance decreased significantly. The authors suggest that this was due to the influence of adaptation strategies.(21) It may be that patients become more used to their skin lesions and accept them or gain an improved self-image over time.

The QOL of partners and relatives of people with psoriasis can also be significantly affected. In a study by Eghlileb et al. (3), forty different aspects of the impairment produced in the lives of relatives and partners were identified and assigned to six different domains: treatment, psychological impact, social disruption, sport and leisure limitations, daily activities, and personal relationships. The authors found that the QOL of relatives and partners was more closely related to the patients' QOL than to the objective severity of the patient's disease, as measured by a clinician (3). This secondary impact should also be taken into account when estimating the general burden of psoriasis and when planning the treatment and rehabilitation of patients with psoriasis.

2.3.1 The effect of psoriasis on household chores

According to the author's knowledge, there are very few studies in the literature with a main focus on the impact of psoriasis on household chores, and almost none on the effect of the clinical and socio-demographic characteristics of psoriasis patient on performing household chores.

What is included in the definition of 'daily activities' varies markedly depending on the study. In many cases, this can be assumed to be based on the fact that various household chores form the majority of such activities. However, this is not always clear and often ambiguous terminology prevents direct comparison of findings. In one study, specific daily activities affected by psoriasis were reported to be work around the house or garden, having to wear special clothes and/or having to change or wash clothes more often, and having to take baths more frequently (16). Some studies also include hobbies and leisure-time activities in ‘daily activities’. According to a large European survey of 17 990 people with psoriasis (10), the greatest impact was found to be on activities of daily living, especially in washing and changing clothes, choice of clothes, the need to bathe more frequently, and sporting activities. Approximately 48% of the reported disability could be accounted for by problems related to the activities of daily living (10). Moreover, a study with severe psoriasis (104) reported considerable or a great deal of disability in items related to washing, changing clothes, and clothing choice. The patients also felt they needed to bathe more frequently, had difficulties in sporting activities, and reported that their homes were messy or untidy (104).

Scaling of skin as a frequent psoriasis symptom can lead to patients being forced to clean their house or to change their clothes more often than without such symptom. In a French cross-sectional multi-centre study with 590 patients (11), 14% of the patients with mild psoriasis reported an impairment in their daily tasks but 26% of patients with severe psoriasis experienced such an impairment. In addition, 47% felt they needed to clean the house, e.g. vacuum and change the bed linen more often because of their psoriasis; here there was a significant difference between patients with a history of treatment of psoriasis with phototherapy and/or a systematic agent and patients without such history (50% vs. 38%, respectively).(11) According to a relatively small study of 32 psoriasis patients from a tertiary care teaching hospital in India (105), the need to use different types of clothes because of their psoriasis was mentioned by 88% of the patients and 91% reported that their QOL was affected. Psoriasis does not only affect the life of patients, but it can have also have an influence on the lives of family members and partners. In earlier mentioned Eghlileb et al. study (3), 37% of psoriasis patients’ relatives and partners described the limitations on their daily activities such as shopping, going for an evening walk, or spending time with other family members.

In a survey assessing household productivity with PsA, the patients estimated that they had lost on average 6 days of household work over the previous month, and 4 days of family, social, or leisure activities because of psoriasis. They estimated they had had, on average, 8 days over the previous month when their productivity in household work was less than 50%, and had required 2 days with outside help. When measuring the overall interference of PsA on the productivity of household work, using a scale from no interference (0) to complete interference (10), the patients scored on average 5.0. The authors found that patients in a worse state of health had on average, 2 to 6 times more days affected in the categories previously described compared to patients with a better state of health. The study found that the impact of PsA on household productivity and participation in daily activities was even higher than within the workplace.(106) However, the burden of the disease may be greater among PsA patients compared to non-arthritis patients as has been suggested earlier (83).

Increased skin care due to psoriasis can be expected to cause considerable burden at least to some patients. The time estimated for skin care at home by patients with psoriasis vary between 4 minutes and 58 minutes per day (11,107). In French study (11), the application of emollients was estimated to take an average of 25 hours per patient per year. In a US study (101), 87% of those with severe psoriasis reported that they used topical medications and spent, on average, 26 minutes each day applying topical agents. According to a European survey (10) the fact that therapy is time consuming was reported by 50% of respondents as being the most troublesome aspect of the treatment, while this aspect was reported by 32% to be treatment ineffectiveness. These findings are in concordance with the US study (101). Nevertheless, in the European survey only 32% of all respondents reported using a topical prescription treatment (10).

In a study with 369 patients with severe psoriasis (104), i.e. patients who were being admitted for in-patient care or starting systemic therapy, 49% of the patients stated they would be prepared to spend 2 or 3 hours each day on treatment of the skin if this would result in normal skin for the rest of the day; the mean time for this for the whole patient sample was 1 hour 40 minutes. Comparable results have been shown in a study from the Nordic countries (103), where the average daily treatment time was 87 minutes per day. In this study, women were prepared to spend more time than men on treating their skin each day, if there was a daily treatment that could clear their skin completely (103).

Twenty-seven per-cent of psoriasis patients have reported receiving assistance from their family or friends. For patients with severe psoriasis this proportion was 29% compared to 19% for patients with a mild disease. Overall, 7% reported receiving assistance from an employed person, for patients with severe psoriasis the proportion was 9% and for those with mild psoriasis it was 2%. This assistance consisted mainly of moral support and physical assistance with daily tasks.(11) However, 70% of psoriasis patients' relatives and partners stated that the treatment of their relatives or partners with psoriasis resulted in them having to do extra housework, including extra laundry, washing, and vacuuming. In addition, they reported to spend considerable time helping to apply topical treatments (3). The authors focused on the duration of time that relatives and partners spent, and they did not define the amount of time more accurately. Patients with psoriasis seem to have considerable need for assistance because of the disease and this may also cause burden to the helper.

2.3.2 The effect of psoriasis on leisure-time activities

The reported burden of psoriasis on leisure-time activities seems to vary between different patient groups. Sixty-nine percent of 936 hospitalized psoriasis patients in Italy (108) reported difficulties in work or hobbies because of the disease, and also reported that the disease affected their social life and interactions. In an Indian study from tertiary care hospital (105) leisure activities were reported as being affected by 72% of the patients. Problems in public places was mentioned by 64% of the patients, problems in going out socially by 56%, sports by 34%, and habits such as smoking and drinking by 9% of the patients (105). A study from Kuwait (109) showed that physical activities were affected in more than 50% of 330 outpatients; this increased significantly with the increased severity of the psoriasis. The majority of patients reported a reduction in one or more physical activities. In addition, social relationships were reported as being disrupted by more than half of these patients. Overall, sporting activities were reported as being affected by 44% of the patients, but in moderate severity cases this number was 76% and in severe cases 80%. Walking was reported to be affected by 77% of the sample, and in moderate to severe cases by 85%. Outdoor activities, sunbathing, going to the hairdresser, and choosing and buying clothes were affected in nearly half of the cases.(109)

According to a review study by de Korte et al. (16), physical functioning and/or mobility, covering activities such as walking, carrying, climbing stairs, and daily work, were found to be impaired in patients with psoriasis. Social contacts and activities such as contact with family, friends, and neighbours were found to be adversely affected, as were activities in groups, physical recreation activities, going out socially, and going to public places. Patients also reported limitations with social activities when their skin was exposed, such as communal swimming, sunbathing, going to the beach, and using communal changing facilities. Problems with sport activities, sexual activities, and visits to the hairdresser were reported. Relationships with families, relatives, and friends, as well as the establishment of social contacts and new friendships, appeared to be impaired.(16) In an American study (110) with moderate to severe psoriasis patients, 83% would often or always avoid activities like swimming and sports because of their psoriasis, and 35% were often or always inhibited in their sexual relationships because of their psoriasis. Sports activities was the area of daily living where psoriasis had most affected, as mentioned earlier (10).

Also 44% of psoriasis patients' relatives and partners have described limitations on holiday plans, sporting and leisure activities and, nights out. These limitations were caused by the timing of hospital treatments and by embarrassment about swimming together. It was also caused by not being able to take their children to a swimming pool because the children felt embarrassed by their relative's condition when the patient was with them.(3) This type of complaints may be considered as extreme examples of the influence visible psoriasis symptoms may cause to psoriasis patients' close ones.

As mentioned earlier psoriasis may have considerable effect on sporting activities. In an observational cross-sectional Italian study (111), 24% of psoriatic patients related that they had regularly carried out sporting activities before the onset of the skin disease . The number of psoriasis patients performing sports activities at the time of that survey was 11%, which according to the authors indicated that psoriasis represented an enormous obstacle to continuing to practice physical activities. This study was conducted among three groups; 416 sportive subjects, a sex and age matched control group (n=489), and 400 psoriatic patients without PsA. The psoriasis was found to be significantly more common in the control group in contrast to sportive group, 5% vs. 2%, respectively. The number of subjects performing sports activities was significantly lower in the psoriasis group compared to the controls, 11% vs. 21%, respectively.(111) Similar trend of reduced participation in moderate to vigorous physical activity among psoriasis patients has been also reported elsewhere (112). On the other hand, little is known about the relationship between physical activity and the onset of psoriasis. Balato et al. (111) suggested that regular physical activity, defined as any muscular action resulting in bodily movement requiring energy, might lower the risk of psoriasis. The authors continued to state that physical activity may have a beneficial effect on the natural course of the disease, modulating not only the severity as well as the incidence of metabolic comorbidities, but also possibly affecting the onset of the dermatosis and its relapses through epigenomic, metabolic, anti-inflammatory and psycho-emotional effects (111).

The Balato et al. findings (111) are in concordance with the findings of a study by Frankel et al. (113) with 86 655 US female nurses who did not have psoriasis the baseline of a 14-year follow-up period. In this study, increasing physical activity was inversely associated with the risk of psoriasis, and vigorous physical activity was independently associated with a reduced risk of incidences of psoriasis. The authors concluded that participation in vigorous exercise equivalent of 105 minutes of running or 180 minutes of swimming or playing tennis, may be associated with a 25% to 30% reduced risk of psoriasis compared with not participating in any vigorous exercise.(113)

2.3.3 Factors related to the perceived burden of psoriasis

Psoriasis has been reported to cause different amount of burden to the patient with different sociodemographic background and severity level. In Italian study (108), with hospitalized psoriasis patients, difficulties in performing work or doing hobbies and the negative effect on their social life and interactions were associated with the severity of the psoriasis. In addition, problems with work or hobbies were more frequently reported by women and by patients in the age category of 40-49 years. Social life was particularly impaired in patients over 30 years of age, with a later age of onset, and a longer duration of the disease. Problems in interactions with others were associated with older age and a low educational level.(108) On the other hand, male patients with psoriasis as compared to female patients reported a significantly higher amount of money that they would be willing to pay for a hypothetical cure, without pain, itching, burning, tightness, pulling, or stinging in the skin (99). This might indicate that men perceived more disadvantages from psoriasis than women; however, there are more opposite findings (95,102,108).

In a large US study (101), older patients more frequently reported difficulties in activities of daily living, such as using their hands, walking, sitting-, or standing for long periods, than younger respondents. Another American study with 317 psoriasis patients (90) found that increasing age was associated with poorer physical functioning but with better mental functioning; the physical functioning included: vigorous or moderate activities, lifting/carrying groceries, climbing several flights of stairs, climbing one flight of stairs, bending/kneeling, walking a mile, walking several blocks, walking one block, bathing/dressing.

Psoriasis is often a highly visible disease, e.g., with lesions on the scalp, neck and hands, and this could cause cosmetic disturbance and changes in patients' social behavior. In a study with moderate to severe psoriasis, 83% of the patients reported that they often or always needed to hide their psoriasis, and 74% claimed their self-confidence was often or always affected by their psoriasis (110). A frequent experience of patients with psoriasis, due to the visibility of the disease, has been reported to be stigmatization (20,114). A stigma has been defined as a biologic or social mark that sets a person apart from others, is discrediting, and disrupts interactions with others (115). A study from Kuwait (109) showed that the ability to meet people and make friends was affected in 48% of the patients because of psoriasis, and worrying about what others may think and reactions to those around affected approximately two thirds of the patients. Feeling embarrassed and depressed was the most frequently encountered psychological effect, both found with an increased severity-level (109).

A higher prevalence of psychological distress in women as opposed to men has often been observed in psoriasis (102,116). In a review article by Raho et al. (95), the authors mention that the prevalence of depression and anxiety in the studies ranged from 10% to 48%. Furthermore, according to the authors, feelings of embarrassment or lack of self-confidence can result in avoidance of public places or situations where skin is exposed, thus reducing social and even employment opportunities and inhibiting relationships with others. They also stated that women scored higher than men with regard to anxiety and depression, disability, and the experience of stigmatization.

(95) Similar results was shown in a study from Italy (108), where emotions that were most frequently experienced by patients were: depression, shame, worry, anger, embarrassment, and annoyance. All these problems were associated with the severity of the psoriasis and with depression or anxiety. All the emotions were experienced more often by women than by men. A trend with age was not observed. In addition, shame and anger were more common among patients with a low level of education, and with a longer duration of the disease.(108) A study from the Netherlands with 128 patients with psoriasis (117) estimated, with the use of multiple regression analyses, that higher levels of fatigue, perceived helplessness, and less social support best predicted the psychological distress of patients with psoriasis. Wide range of measurements have been used to measure the burden of psoriasis.

In addition, in earlier mentioned US study based on the National Psoriasis Foundation Patient-Membership Survey (101), the 17 425 mail-survey respondents in the 18- to 34-year age range and the 35- to 54-year age range reported a greater impact of psoriasis on psychological aspects (interacting with family/spouse, making/keeping friends, excluded from a public facility) of their lives than those respondents 55 years and older. In the same study, using a subsample of 502 telephone survey respondents with severe psoriasis, those aged 18 to 34 years, compared with other age groups, were more likely to report emotional suffering due to psoriasis. Among this group, 88% were concerned with the fact that the disease would worsen; 81% reported feeling embarrassed when people viewed their psoriasis; 90% reported feeling frustrated with ineffective treatments; 75% reported feeling unattractive; and 54% reported feeling depressed.(101) This large survey demonstrates well the magnitude of the impact psoriasis has on patients. Taking into account the chronic nature of the disease and thus the long duration of the effects, the importance of psychosocial aspects to the lives of patients should not be underestimated. Nevertheless, 57% of psoriasis patients' relatives and partners described psychological symptoms including anxiety, feeling down, upset, unhappy, and worried about the patient's condition and possible side effects from the systemic drugs (3). In addition, 55% described the social disruption caused by e.g. the time required for care duties which resulted in less time for social activities such as visiting friends (3).

Same association of severity level and negative emotions, as reported earlier (108,109), was demonstrated in a study by Delfino et al. (99) who found that patients who stated that their psoriasis affected their social or emotional health had a significantly higher body surface area covered by psoriatic plaques than those patients who did not think psoriasis affected those domains. The median amount of money patients would be willing to pay for a hypothetical cure was significantly higher for patients less than 40 years old in the social and emotional areas of life than the older patients (99). Also those patients with a university or medium level of education have reported lower total severity and less impact on their QOL and psychosocial life than subjects with a basic and skilled education (103).

Psoriasis can also have an effect on intimate relationships e.g. sexual relationships. Psoriasis has been reported to affect sexual activities among 33 - 69 % of the patients (105,109). In the US, psoriasis patients under 55 years of age reported more frequently that they had difficulty with sexual activities (27%) than the respondents who were 55 years old or older (13%).

Patients with severe psoriasis, who also had diabetes, asthma or bronchitis, predominantly replied that it would be better to have the comparative disease than psoriasis. This was stated by the authors to confirm the impression that patients with severe psoriasis suffer significant disability, which result in a considerable handicap (104). Psoriasis is a considerably widespread disease among the world's population, as confirmed by the WHO listings (2). There seems to be a relatively good consensus in the literature that psoriasis has a mostly negative impact on performing household chores and leisure-time activities, even though the number of research studies focusing on this aspect remains limited. Furthermore, the definitions of both household chores and leisure-time activities have not been consistently applied. The literature also demonstrates quite clearly how patients' QOL has been decreased because of psoriasis.

2.4 Rheumatoid arthritis

Rheumatoid arthritis (RA) is a chronic inflammatory, immune-mediated disease with a prevalence of 0.3-1% worldwide depending on the geographical region, and the gender and age of the patient (118-124); approximately 70 % of the patients are women (41,125). The prevalence has been shown to be more common in developed countries (123,124), and with increasing age (119), however, it is most common among those aged between 40-70 years of age (41,125). In RA, chronic synovial inflammation and hyperplasia cause articular destruction and bone erosion, leading to functional decline, disability and pain (126-129). Due to its autoimmune nature, RA is not currently considered curable. Patients with RA have an increased risk of mortality compared with the general population (89). Pain and stiffness of joints, especially in the morning, are the most common symptoms of RA (125,130). In addition, pain decreases the patients' functional ability (131).

RA causes several types of disadvantage to patients (6). According to a large review study by Cutolo et al. (132), RA is associated with multiple comorbidities and psychosocial impairments, fatigue, depression, cognitive dysfunction, reduced work performance, work disability, and decreased QOL. Negative effects of RA have been reported to recreational activities, family life, relationships with friends, sexual activities and intimate relationships (13). The increased levels of pain in RA have been associated with higher disease activity, anxiety, and female gender (133). Consequences of fatigue are severe and influence both everyday responsibilities and leisure time (134). In a questionnaire study with 252 RA patients from the Netherlands (135), the most frequently mentioned barriers for not being physically active were a lack of energy, the presence of pain, a lack of motivation, a lack of information, and a fear of joint damage. Pain has been stated to result in constant efforts to cope with everyday life, possible impaired function, and decreased psychological well-being (127). In a study based on the records of all adults in Ontario, Canada (136), compared with a matched control group, individuals with RA were found to be statistically more likely to be obese, less educated, physically inactive, and have a lower income; a statistically higher number of comorbidities and a lower QOL was also reported.

Many instruments measuring impairments in body structures and functions in rheumatic disorders are available. A review study from the Netherlands (137), analyzing the construct validity of these instruments, found 42 different instruments, and also found that those measuring sensory functions including pain, mobility, and mental functions were the most popular. The Committee on Outcome Measures in Rheumatoid Arthritis Clinical Trials (OMERACT) has devised a core set of outcome measures recommended to be used in RA, including: pain, tender joints, swollen joints, patient's overall opinion, clinician's overall opinion, function and radiographs (138).

The health assessment questionnaire (HAQ) (30) published in 1980 was a major milestone in rheumatology, and is still the most widely used questionnaire assessing changes in RA patients' functional ability in everyday life. The HAQ includes a scale of 20 activities of daily living in eight categories in order to assess functional disability. There are four patient response options: without any difficulty = 0, with some difficulty = 1, with much difficulty = 2 and unable to do = 3. The eight categories, each of which includes two or three activities of daily living, addresses the activities of: dressing, rising, eating, walking, bathing, reaching, gripping, and performing errands.(30) The original HAQ and several of the later modifications are by far the most commonly used measures, particularly when estimating functional disabilities among RA patients (30,139).

More than three decades ago, Canadian researchers developed The McMaster Toronto Arthritis (MACTAR) Patient Preference Disability Questionnaire (140), a disability questionnaire based on the functional priority preference of patients, which tried to ensure that improvements in the most important disability/disabilities experienced by the patients were assessed. In that study the list of disabilities due to RA were solicited using a spontaneous listing by patients together with the list of disabilities offered by the interviewer, with the patients being asked to rank these activities in order of importance. These were then compared to existing questionnaires. They found a considerable variation in the disabilities described and those used in conventional questionnaires.(140) The MACTAR has been reported as being valid and a highly responsive instrument for assessing change in the functional ability of patients with early RA as an active disease (141). Only 48% of the impaired activities named by the RA patients were covered by the HAQ, the most commonly used questionnaire to assess changes in RA patients' functional ability in everyday life (141). Nevertheless, the MACTAR study was clearly not based on the spontaneous preferences of patients, as the interviewer offered them a menu of items from which the patients chose the most suitable.

The severity of RA has been commonly studied using the numbers of painful or swollen joints, the severity of the pain, global health indices, and by assessing clinical disease activity or functional ability (142). Later studies have shown that the disability items spontaneously generated by patients are different from those chosen by rheumatology health professionals (142,143). When employing the Disease Activity Score (DAS), functional capacity has been found to be strongly influenced by the disease activity throughout the course of RA, even in longstanding RA (144). Parallel results between the physical component and the disease activity in RA and other chronic inflammatory diseases was also reported in a study by Salaffi et al. (23), even though the perceived severity of RA to the patient could be different from that measured clinically (143). In many evaluation instruments and outcome measures, the importance of the ability to perform physical functions, is emphasized. The patients' perspective and the patients' perceived ability to perform has particularly gained increased attention recently.

Patients' QOL and general well-being can be measured by various instruments. QOL has been found to be significantly affected in patients with longstanding RA, particularly physical role functioning, physical functioning, bodily pain, and vitality (145). Patients report that these facets of the disease may be more important than the traditional clinical measures from their perspective (143). Short Form 36 (SF-36) can be used for measuring QOL among RA patients. All eight health concepts of the SF-36 scores in both the physical component summary and mental component summary have shown significant impairment in patients with inflammatory rheumatic diseases: RA, ankylosing spondylitis, axial-, and peripheral psoriatic arthritis, when compared to controls. The dimensions typically affected were found to be physical functioning, limitations due to physical functions, and bodily pain. Among these diseases the one where patients were found to have the worst QOL was RA. Their multivariate analyses revealed that the physical component was influenced by a high disease activity and comorbidity.(23)

As mentioned earlier, RA may significantly decrease a patient's QOL (132,145,146). In a Portuguese study (147), quite a few, 32.3% of the patients answered that RA was a disease that has an impact on their QOL. The effect of a chronic disease on patients' QOL may not entirely depend on the clinical manifestations of the disease, but can also be affected by a patient's sociodemographic background. According to Sprangers et al. (4) patients who reported the poorest level of QOL with a chronic disease were in general: older, female, had a low level of education, were not living with a partner, and had at least one comorbid condition. Similarly, in an American review study (148) patients with RA who were older, female, less educated, unemployed and/or less affluent tended to have significantly lower QOL than other groups. In one study patients' QOL was more negatively impacted in the early stages of RA rather than later in the disease (149).

Decrements in QOL, especially reduced physical functioning, has been associated with an increased probability of no longer being able to work or engage in housework, absence from work due to RA-associated sickness (absenteeism), and reduced productivity while at work or in the home (presenteeism); all of which have personal and economic consequences for the patient (24). According to several studies, a decrease in participation in non-vocational activities, especially leisure-time activities, may occur during the course of RA, and it may be associated with a reduced QOL and psychological distress (150-152).

2.4.1 The effect of RA on household chores

A Swedish cohort study with a follow-up of 8 years after diagnosis (153) noted that even basic daily activities were affected in patients with early RA. The burden may begin immediately with the disease onset, and not only when the disease has developed and caused more notable tissue damage. Many symptoms of RA affect patients' daily activities. Pain and fatigue has been shown to affect patients' ability to perform unpaid work and household activities (154-156).

In a Finnish study (157), one or more functional disabilities affecting everyday life because of RA was mentioned by 87.4% of the patients with the most commonly mentioned disabilities being walking, opening jars, carrying, lifting down articles, and vacuuming. In one study with 253 RA patients, more than 53% of the patients reported being unable to perform household chores (158). Similarly, in another study the ability to do shopping, housework, and social activities had been negatively influenced for more than half of the patients (159). In a qualitative questionnaire study by Allaire et al. (32), type of reduced household work because of RA that was mentioned were: cooking, after-meal cleaning up, shopping and errands, taking care of others, general cleaning, and laundry. In one qualitative interview study, many dilemmas were mentioned in the category titled caring for household objects, which included e.g. gardening, house repair work, shovelling snow, watering pot plants, sewing, and one entitled family relationships, which included e.g. socialising with grandchildren, taking care of children, socialising with the family and close relatives (160). In an American study (152), the activities most often affected by RA were reported to be gardening (87%), heavy housework (85%), minor repairs (82%) and paid work (73%). In RA literature, the concept of household chores seems to include the whole variety of activities which are associated with perceived burden.

Ability to perform household chores may be important from patient perspective. It has also been suggested that patients perceive RA to cause greater burden to household chores than work (152). Osterhaus et al. (161) found that the rate of RA interference with household work was reported as slightly higher than the rate of reported work interference; the mean for household productivity was reported to be 5.8 (scale 0 = no interference, and 10 = complete interference) and the mean for work productivity 4.5. In another study 31.8% of the patients with RA expressed a high level of difficulty in performing activities of daily living, whereas only 24.7% said it affected their ability to work (147).

In a multicenter study with 220 RA patients with a moderate to severe disability and low physical QOL (161), 75% reported having missed days of household work over the previous month, 86% had days where their productivity was less than or equal to 50% in household work, and 94% reported the interference of the disease with their productivity at home. In another study activities of daily living that the patients found difficulty performing due to the disease were gardening and performing household chores with both producing mean score above 5 in a scale of difficulty with 10 as the maximum score; thus, indicating extreme difficulty (147). Reinseth et al. (151) discovered that there had been a significant decrease in non-vocational (home and leisure time) activities during the last 10 years among patients with RA. In their definitions, non-vocational activities included both home and leisure-time activities, meaning that the findings from their study are difficult to compare with those from studies separating household chores and leisure-time activities. A Dutch study among 346 RA patients (162), showed that 18% felt that RA had been a major obstacle to household activities, 68% felt it had been a partial obstacle and 14% had not experienced any influence of RA on these activities. These studies indicate that RA has considerable burden in perfoming household chores.

However, in the Finnish study referred to earlier (157), the most commonly mentioned functional disabilities affecting everyday life were stated not to be those where the subjects reported the highest perceived disabilities. In contrast, those functions requiring physical strength, like beating carpets and washing windows were stated to be activities where the subjects had the most difficulty coping. In the same study, disabilities related to lower extremity functions were reported as being considered the most disabling, whereas upper extremity and finger functions were not perceived as causing a handicap.(157) A RA related reduction in functional ability seems to be associated with patients' perceived disability when performing household chores.

In many households, women can be expected to carry out more household chores than men (162). In previously mentioned study (32) among women with RA, those patients with more severe RA reported significantly greater reductions (-29%) in the proportion of total household work they presently did to the amount they did just prior to the onset of RA, or among the non-RA group 10 years ago. The comparison was made with both the non-RA (-9%) and the mild RA (-9%) groups. The functional status was reported as being significantly associated with reductions in the amount of household work done.(32) Women may feel that it is important to cope with household chores. When evaluating the relative importance of the 20 functions of the HAQ for patients with RA in their everyday life, men were found to assess the highest importance to the ability to walk outdoors on flat ground and women to dressing themselves, getting in and out of bed, and washing and drying their body (142).

The prevalence of RA is about two times higher in women than in men (118). In most studies, women comprise the majority of study participants (70-85% vs. 15-30%) (8,128,150,154). Studies comprising of solely female patients have many times dealt with the perceived disadvantages when performing household chores (32,151,163).

Women with or without RA were not found to differ in the amount of weekly time spent on household work among groups, of mild RA (36.2h), more severe RA (35.6h) and non-RA (36.0h) (32). A Canadian study examining paid and unpaid work among RA patients (154), stated that working aged women with RA performed significantly more hours of household work (19.36 vs. 9.36h), care-giving (6.59 vs. 2.47), and volunteer work (1.27 vs. 0.47), and less home maintenance (2.39 vs. 3.84) during the preceding week than men. Similarly, in a study from the Netherlands (162), men spent less time in housekeeping than women: 6 and 17h a week, respectively. As a whole, the Dutch population was reported to perform household activities for 19h a week on average, with a large discrepancy between males and females (10 and 27h a week, respectively). However, the overall Dutch population cannot be considered comparable to RA patients. It was concluded that when considering performing household activities the difference between men and women was approximately of the same magnitude among RA patients and general population.(162)

In addition, in a large multinational study (128), including 6 004 RA patients from 25 countries, measures appeared to be worse in women than in men. Among the women with RA, the mental health status has been shown to be of greater importance than the physical functions needed to perform non-vocational (home and leisure time) activities in daily life (151). It may well be that women perceive significantly more disadvantage in performing household chores than men. Moreover, concomitant psychological and mental problems can be more handicapping among female rather than male RA patients.

In a study among 48 housewives with RA (163), 68.8% of the patients were mentioned to be unable to do at least one household activity, and of these, 91% were unable to clean the house, 84.8% were unable to wash the floor, 54.5% were unable to take care of their children or husbands, 45.5% were unable to wash the dishes and 30.3% were unable to cook. In addition, disabled housewives had significantly more children and their husbands earned less money, but there was no significant difference in the presence of clinical indicators such as (rheumatoid factor) RF, erosion, swollen joints, and tender joints, but disabled housewives had a trend towards a longer period with a symptomatic disease (163). Socioeconomic factors may be the reasons that, at least partially, explain the disadvantages female RA patients perceive, instead of the solely clinical indicators. A lower economic family status seems to be connected with less ability to manage household chores. Reduced ability to work, increased sick-leave, and other economic consequences, such as, the cost of outside assistance may further increase the burden on RA patients (18). It is worth noting that the Habib et al. study (163) was conducted among Arab housewives. Cultural factors may have had a strong influence on the findings and they should not be directly generalized to western cultures.

It was appreciated that women may perform more household chores than men (162). Another study concluded that women with RA perform household chores in an equal amount as women without RA (32). This may indicate that there are certain household chores, which remain necessary for women to do, irrespective of the disease burden. Furthermore, women with RA are probably in many cases forced to rely on assistance from other family members or from outsiders in order to complete the necessary household chores (8,32). It seems that a chronic disease like RA does not cause a gender-neutral burden in household chores.

Because of the disease, RA patient may need help in performing household chores. Sixty percent of RA patients reported to have received unpaid help at some point and 27% have reported to receive paid help during the previous 6-month period (158). In a study with an overall mean disease duration of 7 years, 51% of the patients had needed help in household chores, 34% from their relatives, 7% from friends, 12% from formal home assistance, and 15% from private household help (8). Westhoff et al. (164) estimated that among the 273 RA patients, more than 50% with considerable disability (HAQ 1.5-2.3) had required help in activities of daily living, and for those patients with less than 30% remaining of their functional ability (HAQ > 2.3) the need for help had been almost certain i.e. more than 95%. In a study from the Netherlands (8), RA patients receiving informal care were found more likely to be women, after adjusting for disease duration, QOL, and age. In the same study, on average, the male patients needed 2.8 hours and female patients 3.8 hours of informal care per week. Formal care was reported to be required for an average of 0.3 and 1.4 hours a week by male and female RA patients, respectively.(8) Care duties were not specifically classified, but household chores may be expected to cover majority of them.

Strand and Khanna discussed in their study (12) that patients often have to seek additional support to meet their individual role obligations and this may include assistance from family members / hired household personnel, or asking their employers to be more flexible in terms of attendance/performance. Such situations may be troublesome to individuals who have been self-sufficient previously, but with the onset of RA symptoms are required to request assistance in order to manage even the most necessary household chores. Strand and Khanna argued that all of these factors combine as an additional personal financial burden reflecting the diversity of the impact of RA (12). In the early stages of the disease, within three years after diagnosis some patients already need help in household chores and transportation (159). In addition, 18% of the RA patients with moderate to severe disability (mean HAQ-DI of 1.5) and low physical QOL had to employ outside help (161).

Several types of adaptive aids and devices to ease the performance of household chores are available for RA patients. According to Maetzel et al. (158), almost 20% of the patients with RA had purchased adaptive aids and devices in the previous 6 months compared to 7.9% of those with osteoarthritis (OA) and 0.7% with hypertension in the same study.

The need for assistance in household chores may vary according to the severity level of the symptoms. Patients receiving (in)formal care have been found to be more likely to have more functional disability, even after adjusting for disease duration, QOL, and age (8). In Allaire et al. study (32), patients in the group with more severe RA have reported that their other family members spent significantly more time on total household work per week than their peers in the families of the non-RA subjects and the subjects with mild RA. In that study, the group with more severe RA did not mention more use of paid household employees than the non-RA group.(32) However, that study sample was comprised solely of women and it is possible that female patients are more likely to try to manage household chores by themselves, even with their difficulties. On the other hand, in a study among 48 Arab housewives with RA (163), 75% of those with perceived disability were helped daily, whereas 43% of those without disability received daily aid in running the house. The cultural characteristics of the study settings may explain the observed differences.

2.4.2 The effect of RA on leisure-time activities

RA has been shown to have a strong influence on patients' selection of leisure-time activities, time consumed, and the ability to perform them. According to several studies, RA may impair patients' ability to engage in family, social, and leisure activities (32,150-152,163). The Norwegian RA patients had reduced their participation in LTPAs by almost one-third during the preceding year (36). In that study, LTPAs were classified as active (5-9 LTPAs) or less active (0-4 LTPAs) according to how many LTPAs they performed. The less active individuals had reduced their performance in LTPAs to a much higher degree than the active individuals during the preceding year.(36) In a Swedish prospective RA study (165), approximately 8 years after the onset of the disease, three-quarters of the patients had been forced to alter their leisure time activities and half of them were not satisfied with their recreation activities. In addition, 72% reported an activity they would have liked to do but could not. Higher levels of emotional distress were associated with these handicaps.(165) The burden of the disease in leisure-time activities seems to be considerable.

Various activities included in the concept of leisure-time activities have been reported also in RA literature. In a qualitative interview study (160) among patients with a three years post-RA diagnosis, most reported dilemmas in everyday life in a category entitled recreation and leisure, which included e.g. walking, jogging, playing soccer or bandy, going to the cinema, playing computer games, dancing, fishing, visiting swimming halls, travelling, being out with friends. In another study (159), also after an average disease duration of three years, the ability to do shopping, home work, leisure-time activities and social activities was found to be negatively influenced by the disease in more than half of the patients. Practicing sports has been reported to be particularly difficult leisure-time activity among RA patients (147).

Significant decline has been reported in physical activities. In a Dutch study comparing 252 RA patients to general Dutch population (166), physical activity per week was found to be significantly lower in the RA population compared with the general population in the category of 45 to 64 year olds (1856 vs. 2199 minutes, respectively). However, the difference in the category of over 64 year olds was not found to be significant (1115 vs. 1218 minutes, respectively) (166). Inactivity has also been found to be related to increased medical costs in patients with arthritis (167). In the Sverker et al. study (160), some participants had to refrain from leisure activities due to RA. Several patients reported they had had to reduce the time for recreation and leisure activities due to fatigue after work. Some patients reported that they had replaced demanding physical activities with less demanding activities, e.g. bicycling with friends instead of walking together, and some had reported continuing to participate in their activities of interest but had been forced to adjust how they performed them, or performed them in the same way as previously, and accepted the pain.(160) A qualitative interview study from the UK (168) underlined that people with RA may cope differently, some in an active and positive way by altering their activities over time, from daily to taking a year-long break from a particular hobby, others by changing the activity to a more manageable activity. Patients with worse coping strategies may perceive more burden from the disease.

According to a Swedish study (150), at baseline RA patients performed less but did not have significantly less interest in leisure activities compared with controls. In that study, no loss in the leisure activities performed was seen during the on average 3.2-year follow-up, and no significant predictors were found for individual change. Furthermore, leisure activities did not show improvement despite the reduced disease activity during the follow-up.(150) In another Swedish study (34), active leisure activities, e.g. walking, bicycling, swimming, going to the gym, and gardening had increased during the 2.8-years follow-up, while mixed pattern of active and passive leisure activities, e.g. reading, clubs, theatre, dressmaking, and social gatherings had remained unchanged. However, the change in active leisure activities did not correlate with the predictors evaluated, such as the HAQ, VAS pain, on average VAS global assessment, QOL, or sociodemographic variables. The authors suggested that values other than those evaluated may be important, including coping strategies, depression, fatigue, and social interaction.(34)

A chronic disease such as RA presents a challenge to the balance in everyday life, as reducing the ability to perform leisure-time activities is expected to have a negative effect on ability to perform in work (5,150). Only a few decades ago physical activity was not recommended for patients with RA. The belief was that extensive use of the affected joints could cause severe harm.(169) However, more recent studies contradict this assumption, and current opinion among rheumatologists is that high-intensity weight-bearing physical exercise prevents joint destruction and increases functional ability in daily life in patients without pre-existing extensive joint damage (19,170,171).

Nowadays, there is considerable evidence that regular physical exercise reduces the disability, fatigue, and pain in patients with RA (17,172). Studies indicate that even easy and moderate levels of physical activity can enhance health, although a higher intensity increases health gains in patients with RA (17,170). Feinglass et al. (173) stated that even modest increases in levels of physical activity among older adults with arthritis may play a considerable role in decreasing disability. Walking, for instance, is recommended as a safe activity with which to decrease cardiovascular risk in RA. It seems that even moderate physical activity increases RA patient’s functional ability and reduces the risk of comorbidities, which is known to be increased in RA patients.(174) On the other hand, only a quarter of the RA responders in Reinseth et al. study (36) were physically active in their leisure time.

In a Swedish study (175), the majority of the patients with RA had a decreased measure of physical fitness in their lower-limb muscle function, grip force, joint motion, and functional balance when compared with norm data, even though their physical disability was not severe (median HAQ 0.63). It is interesting that in this Swedish study, the self-reported physical activity behaviours of RA patients were similar to those in the general population, with almost 50% failing to meet recommendations on healthy physical activity (175). Similar findings have also been found in Canada (176) when comparing RA patients with the general population. Nevertheless, the Swedish study found that correlations between physical activity and physical fitness, demographic factors, general health perceptions, pain, activity performance, and disease activity were all very low (175). There seems to be vast differences between countries in the rates of participation in leisure-time physical activities by people with RA/arthritis. In the Netherlands (166), the proportion of RA patients meeting the Dutch public health recommendation for physical activity was 58% and there was no difference compared to general population. In Canada (176) 56% of the individuals with rheumatic conditions, including RA, were engaged in regular leisure-time physical activity, which was emphasized as important for improvements in health conditions. On the other hand, in that study only 13.2% of the women and 18.9% of the men with rheumatic conditions were sufficiently active (176). In the USA (177), among individuals with self-reported arthritis, including RA, only 24% reported reaching the recommended physical activity level. The above-mentioned study findings should not be directly compared, as both the diagnostic criteria as well as the definitions of physical activities in the studies varied.

In a questionnaire study of 252 RA patients from the Netherlands (135), 80% of the patients reported participating in some type of physical activity or exercise. Of the active people, 22% were found to participate exclusively in supervised activities, 36% in unsupervised activities, and 42% in combined supervised and unsupervised activities. From the list of 11 predefined activities, cycling and walking were mentioned to be the two unsupervised activities people performed most often. Supervised group exercise and unsupervised individual physical activity were reported as favourite activities, and more people mentioned they preferred water-based over land-based activities.(135) In a study (176) based on a Canadian National Population Health Survey, walking was also found to be the most frequently reported LTPA participated in the last 3 months, both among those with and without rheumatic conditions. The next most popular forms of activities in both groups were home exercise, swimming, dancing, gardening, and bicycling (176). Similarly, in another study, walking (strolling) and walking in the woods were mentioned as the most common LTPAs performed both by active and less active individuals even though the active individuals performed these activities to a much higher degree (36). On the other hand, according to an American study (152), the activities most often affected by RA were gardening (87%), heavy housework (85%), minor repairs (82%), physical activities (moderate, 80%, and vigorous, 78%), hobbies (75%), and paid work (73%), and these activities also had the highest mean difficulty ratings. Mental health status seemed to be of greater importance than physical functioning when performing non-vocational (home and leisure time) activities in daily life among women with RA (151). There were indications that a high number of activities performed correlated positively with scores on psychological well-being, and that a low amount of activities performed correlated with the psychological distress scores (151).

Older age brings deterioration of body functions, irrespective of diseases. Physical activity slows down this process and has rehabilitative effect at all ages. Chronic disease, like RA can decrease the frequency and intensity of physical activities. In the study by Reinseth et al. (36), high levels of LTPAs among RA patients were significantly associated with a younger age. This finding was corroborated in a Dutch study (135) in which the more inactive people with RA were older compared to the more active people with RA. In addition, the Eurenius et al. study (175) showed that those less physically active were aged over 65 years and those more physically active were aged 65 or under. In a large RA cohort study over five years, with 863 RA patients and 1 176 community controls (178), the HAQ scores increased by 0.01 units per year in both cohorts, and the authors suggest that the progression of functional disability among patients with RA and the population in general is largely explained by the aging process. When estimating the effect of RA on physical activity, it is important to control for age as a confounding factor. It has been said that even modest increases in levels of physical activity among older adults with arthritis can play a considerable role in decreasing disability (173).

Several studies (128,173,179,180) have shown that women with arthritis may have a significant risk of functional decline and more pronounced limitations in activity than men. In one study (175), the older women (>65 y) with RA were especially less physically active than the younger women. In a Norwegian study (36), the females with RA reported having reduced their participation in LTPAs by almost one-third during the previous year. Wikström et al. (150) described that from an interest checklist of 20 domains of outdoor activities, including gardening, exercise, ball sports as well as music and entertainment, female patients were found to perform the activities significantly less frequently when compared to control group members. In contrast, the men with RA, were found to perform less frequently outdoor activities, watching TV or going to the movies, attending arena sports and cooking when compared to the control group (150). However, Sokka et al. (128) suggested that most of the gender differences in RA disease activity may originate from the measurement tools for measuring disease activity rather than from RA disease activity itself. The authors also speculated that because women have less muscular strength than men, the same burden of musculoskeletal disease may be more harmful to a woman than to a man (128).

On the other hand, the opposite findings have also been reported (34). The Wikstrom and Jacobsson study (34) found that men and women with RA participated to the same extent in active leisure activities such as, walking, bicycling, swimming, going to the gym, and gardening, but women were said to have a more mixed pattern of active or passive leisure activities like reading, clubs, theatre, dressmaking, and social gatherings than men. They also found that there were no significant differences between the genders regarding the changes in leisure activities over an average of a 2.8-years follow-up time (34). In contrast, a study from the Netherlands (135) found that significantly more inactive RA people were male. The observed differences in these findings may, at least to some extent, be explained by the differences in study methods employed.

Increased levels of pain, one major symptom of RA, have been found to be associated with the female gender (133), which may be one reason explaining the limitations in activity of women with RA. In a study based on the Canadian National Population Health Survey (176) both moderate and higher intensity LTPA was shown to be associated with less generalised distress, and this relationship was pronounced among middle-aged and older patients and women with rheumatic conditions. The authors of this report suggested that it may be beneficial to recommend regular exercise to specific groups for preventing psychological distress (176).

Those who have had RA for a longer period of time have been shown to have a lower functional status (163,181). However, Pollard et al. (182) found that patients in the early stages of the disease had greater impairments in their physical functions than those who had experienced RA for longer time. It seems that RA already causes a burden to patients in the early stages of disease (153), and not only when the disease has developed and caused more notable tissue damage.

Low levels of education have been discovered to significantly predict a decrease in the performance of leisure activities among RA patients (150). In a Norwegian study (36), the active individuals had a higher level of education, were working to a significantly greater extent, performed vigorous activities more often, and reported better functioning, higher scores on the self-efficacy scales, and lower joint pain and fatigue. According to a previously mentioned Dutch study (135), insufficiently active people with RA were found to be less educated than the more active ones. Educational level was also found to have important association with a negative impact on patients' mental QOL among patients with chronic pain associated disabilities; this being the case with many RA patients (23).

People seek to occupy themselves with leisure-time activities, which they find satisfying and rewarding, and RA patients cannot be expected to be exceptions to this. According to Katzt et al. (183) a decline in the ability to perform recreational activities and engaged in social activities interactions was linked to the onset of new depressive symptoms. The same linkage was not seen in the other 11 valued life activity domains e.g. housework, entertainment, travelling, and writing (183). The loss of especially valued activities has been said to play a substantial role in perceptions of health in RA (5). Studies indicate that people with RA seem to prefer physical activity in groups under professional management, especially water-based activities (135,184).

2.4.3 Factors related to the perceived burden of RA

Multiple comorbidities and psychosocial impairments, fatigue, depression, cognitive dysfunction, reduced work performance, work disability, and a decreased QOL has been reported among RA patients (132). Leisure has been seen as an essential part of occupational performance (185). A chronic disease like RA may present a challenge to the balance in everyday life activities overall. People make every effort to accomplish a balance between meaningful and purposeful work, rest, self-care, and leisure activities (186). In an American interview study of chronic health conditions (5), disability in valued life activities including a wide range of life activities deemed to be important by the individual, ranging from self-care to leisure activities, was found to be strongly associated with fair/poor health in RA, Systemic lupus erythematosus and Chronic obstructive pulmonary disease. According to that study, substantial portions of each group rated their health as fair/poor, 37% and 47% and 40%, respectively (5). Losing the capacity to engage in meaningful leisure activities may have implications for one's identity (187). Prevalence of depression among RA patients has been found to range between 13% and 20% (143). On the other hand, participating in desired leisure activities has been shown to prevent depression in RA (183).

Pain related to chronic disease can have a strong influence on a patient's psychological well-being, when coping with everyday life (127), and have also been associated with anxiety (133). Among 84 early RA patients (159), a high pain level at baseline was shown to produce a four times higher risk for a high level of psychological distress after 2 years. A substantial negative effect on emotional well-being (6), and numerous negative emotions because of participation restrictions in daily and leisure activities due to RA have been described (22). The influences of RA on patients' psychosocial well-being are multiple and diverse. Pleasure producing leisure-time activities can be considered as an important part of every individuals's life, including those suffering from a chronic disease like RA, and they are essential to achieve and maintain a psychosocially balanced life. In addition, all forms of social activities can be considered an essential part of a patient's QOL and a marked reduction can be expected to affect the QOL negatively. Unfortunately, studies have indicated that social activities have been negatively influenced by RA in more than half of the patients (159,161). As well as the effect on social well-being, RA has been mentioned to have a significant impact on patients' financial well-being (188). Patients have reported that when active the disease significantly impacts their private lives, work/social responsibilities, and their self-image (189).

Overall, the author got an impression that the existing literature on RA is much more extensive than that on LBP or psoriasis, and there is more research dealing with the effect of the disease on household chores and leisure-time activities. The findings consistently show that RA has a negative effect on patients' performance in these areas. The most commonly used outcome measure to specify a patient's functional ability, the HAQ, contains items that measure hindrances in daily activities. However, those related to performing leisure-time activities are few. RA is characteristically a disease that affects women more often than men, hence this may be one reason for the many studies dealing with ability to perform household chores.

2.5 The burden of three chronic diseases on patients performing household chores and leisure-time activities

There are several studies concerning the effect of LBP on performing household chores and leisure-time activities, but almost none that focus on the role of the socio-demographic or clinical background factors. However, the role of physical and leisure-time activities and household chores as underlying factors causing LBP has been covered in the literature. This is different from research on other chronic diseases, such as psoriasis and RA, and probably because LBP is not an autoimmune, inflammatory disease; therefore, it has a different nature and the research needs another kind of approach. The fact that psoriasis is mainly a skin disease with visible symptoms is pronounced in the literature. The stigma surrounding the disease and the need for skin care in psoriasis clearly create a different kind of burden on performing household chores and leisure-time activities compared to LBP and RA. Scientific research on RA is far more extensive compared to LBP and psoriasis, although research in this chronic disease on the perceived burden of performing household chores and leisure time activities has also remained relatively scarce.

According to the literature, all the chronic diseases studied have a mostly negative effect on performing household chores and leisure-time activities. These three chronic diseases can cause pain, disability, social, mental, and psychological burdens and they often decrease patients' QOL. All of the diseases have also been shown to have the potential to cause a negative burden on patient's relatives and friends, and may increase the need for assistance in household chores. In many cases, patients with chronic diseases can be expected to experience a significant burden from their inability to perform household and leisure-time activities.

The literature dealing specifically with household chores and/or leisure-time activities is limited. The three chronic diseases under study in this thesis seem to have strong influence on both household chores and leisure-time activities. Considerably more studies would be needed. Good example of this scarcity is the fact that during recent years no other journal articles spesifically focusing on these issues could be found except those of the author and coworkers.

3. Aims of the study

General aim:

To assess how chronic disease affect patients' performance in household chores and leisure-time activities.

Specific aims:

To evaluate the perceived disadvantages caused by LBP in performance of household chores and leisure-time activities.

To evaluate the perceived impact of psoriasis in the performance of household chores and leisure-time activities and to quantify the disadvantages caused by the disease.

To estimate how much outside assistance psoriasis patients receive, and the need for additional assistance.

To estimate the additional time required for skin care at home due to psoriasis.

To evaluate the perceived impact of RA in the performance of household chores and leisure-time activities and to determine the activities most affected by RA.

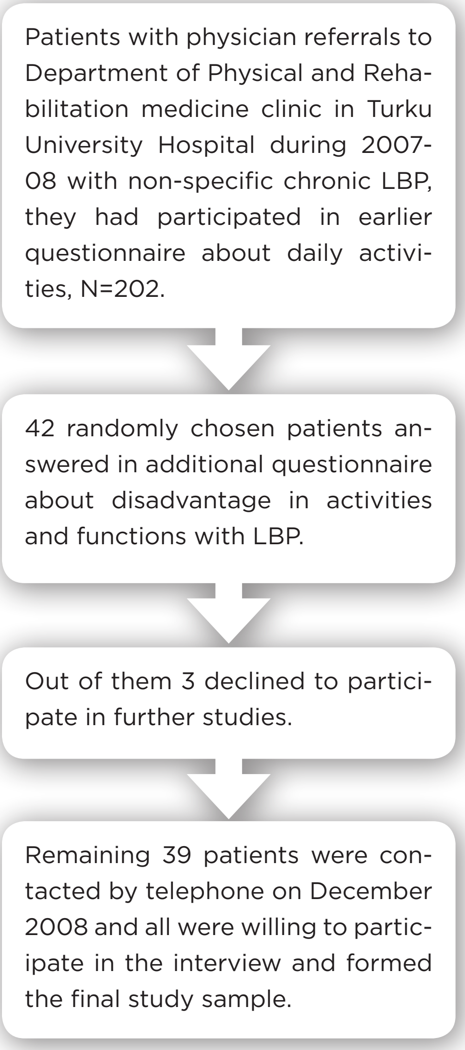
To estimate how much outside assistance RA patients receive and the need for additional assistance.

4. Materials and methods

4.1 Low back pain (I)

4.1.1 Patient sample

The basis of the sample were the referrals by physicians of 202 patients to Turku University Hospital, Department of Physical and Rehabilitation Medicine drawn systematically during 2007-2008 with chronic non-specific low back pain (LBP). The diagnosis, however, had not been confirmed by a specialist in rehabilitation medicine at the time of patient recruitment to the study and the duration of the symptoms was unknown. The criterion for inclusion included these key factors: chronic LBP (minimum 6 weeks) as the primary cause for referral; patients with LBP and also concomitant symptoms of pain in other parts of vertebrae, and pain and/or disabilities in upper and/or lower extremities were also accepted. In contrast, infections, traumas, and malignancy were the exclusion criteria. The sampled patients had participated in an earlier questionnaire studying about how well they managed to carry out their usual daily activities. It was estimated, based on the findings of two pilot studies that by using a sample of about 30 patients, it would be possible to detect factors which affect LBP patients' everyday life. Of the original sample, 42 randomly chosen patients were sent an additional questionnaire asking them to describe, in their own words, which activities and functions were affected by their LBP. Completed questionnaire forms were returned by all 42 patients although three patients stated that they no longer wished to participate in further studies. In December 2008, contact was made with the 39 remaining patients, who formed the final patient sample for this study; these patients were then asked to participate in a structured telephone interview conducted by a trained interviewer. Flow chart of the sample and participation is presented in Figure 1.



Patients with physician referrals to Department of Physical and Rehabilitation medicine clinic in Turku University Hospital during 2007-08 with non-specific chronic LBP, they had participated in earlier questionnaire about daily activities, N=202.

42 randomly chosen patients answered in additional questionnaire about disadvantage in activities and functions with LBP.

Out of them 3 declined to participate in further studies.

Remaining 39 patients were contacted by telephone on December 2008 and all were willing to participate in the interview and formed the final study sample.

Figure 1. Flow-chart of patient selection in low back pain study.

4.1.2 Interview

Interview training for this particular study was undertaken by the interviewer (the author of this thesis) through conducting ten practice interviews with subjects who were unknown and not included in the actual study. As a result of the experience and feedback gained from these practice interviews the question phrasing of a number of the final questions was modified.

All 39 of the patients contacted were willing to participate in the interview (Appendix 1) and all of them completed the whole interview. The time allowed for answering each question was not limited. The telephone call commenced with an explanation of the purpose of the interview. The interview encompassed questions dealing with the effect of LBP on daily life, with separate divisions for work (18), household chores and leisure time. On average the interviews lasted 15 minutes (9-23 minutes).

Socio-demographic background data were collected. The average age of the patients was 46 years (20-73), 29 were women and 10 were men. A dichotomy of 0) younger than 50 years and 1) 50 years and over was formed.

The subjects (39/39) were asked how many hours of help friends and relatives had given them with household chores during one week. The reported time was later transformed into minutes. The ability to perform household chores at the time of the interview was solicited using a numeric rating scale (NRS) from 0 to 100, where 0 represented an inability to perform at all and 100 an ability to perform without any difficulty. They were first asked to assess their ability to perform in household chores with LBP at the moment of the interview, and in the next stage they were asked to estimate their expected performance in a hypothetical situation if they did not have LBP. The differences between reported performances with and without LBP showed the level of disadvantage caused by LBP in household chores.

The NRS scores for the performance of hobbies and leisure-time activities were conducted in exactly the same way as previous assessment, i.e. with and without LBP, and these provided the statistics for all participants when calculating the disadvantage experienced in leisure-time activities (39/39).

The participants were then asked to list those hobbies or leisure-time activities that had been so severely affected by LBP that they had been obliged to either reduce the time spent on these activities or entirely discontinue them. The reported results indicated the number of hours per week they presently took part in each activity the mentioned and the percentage reduction they had been required to make due to LBP. The subjects listed their hobbies and leisure-time activities using their own words, and they were not offered any prepared list of activities to choose from. These were then sorted into distinct categories, including: walking, social activities, gardening and 7 different sporting activities.

The activities were dichotomized as follows: 0: other than sporting activities; and 1: sporting activities. Sporting activities included for example, jogging, all ball games, and gymnastics. Several dichotomies were created based on whether the subjects had been forced to reduce or abandon any leisure-time activities, sporting activities and other than sporting activities.

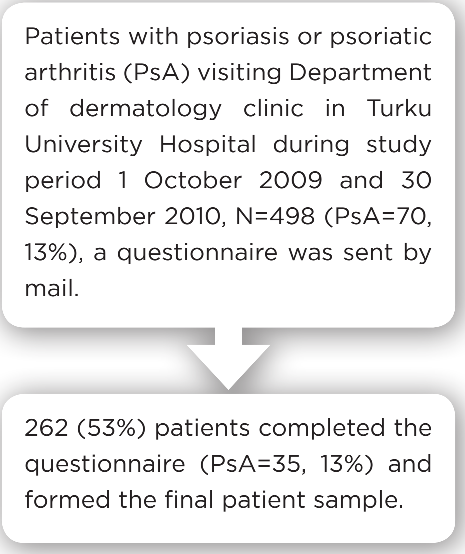
An overall disadvantage figure was obtained by computing a mean score for the disadvantages experienced in work, household chores and leisure-time activities.

4.2 Psoriasis (II & III)

4.2.1 Influence on household chores and time spent on skin care at home (III)

4.2.1.1 Patient sample

Patients who had visited the Department of Dermatology in Turku University Hospital over a 1-year period formed the basis of the sample. All the patients were diagnosed with psoriasis and some with psoriatic arthritis. The Finnish health care system treats patients with mild psoriasis in primary health care settings and only those with moderate-to-severe cases are referred to tertiary level hospital for further treatment. A pretested and piloted questionnaire was sent by mail to the patients; a repeat mailing was sent to those who did not initially respond. During the study period a total of 498 patients attended the clinic (428 with psoriasis and 70 with psoriatic arthritis); of these 262 completed the questionnaire (52.6%). Flow chart of the sample and participation is presented in Figure 2. There was equal participation from both groups of patients with psoriasis (patients with psoriatic arthritis comprised 12.9% of the original sample and 12.7% of the respondents). The mean age of the original sample (55.0 years) was lower ($p<0.05$) than that of respondents (58.4 years). In both the original sample and the respondents, women comprised 45%. No statistically significant differences were found in any of the analyses conducted between patients with only skin symptoms and patients with both skin symptoms and arthritis. Thus, these two patient groups were analyzed as one psoriasis group.



Patients with psoriasis or psoriatic arthritis (PsA) visiting Department of dermatology clinic in Turku University Hospital during study period 1 October 2009 and 30 September 2010, N=498 (PsA=70, 13%), a questionnaire was sent by mail.

262 (53%) patients completed the questionnaire (PsA=35, 13%) and formed the final patient sample.

Figure 2. Flow-chart of patient selection in psoriasis studies.

From the patient records of the respondents who had given consent, Psoriasis Area Severity Index (PASI, n=72), Dermatology Life Quality Index (DLQI, n=36) and diagnosis (ICD-10, n=262) were collected to study the effects of the severity, burden and the type of psoriasis. If there were many PASI or DLQI values from the same patient, the mean value for the study period was calculated and used in the analyses.

4.2.1.2 Questionnaire

In a questionnaire (Appendix 2) a 10-cm-long visual analog scale from 0 to 100 was used to assess current ability to perform household chores, where 0 on the left was labeled as an inability to perform at all and 100 on the right as an ability to perform without any difficulty. The question the respondents were asked was: Mark an 'X' on the line, which corresponds to your current ability to perform household chores.

In the following stage, they were asked to mark an 'X' on the line corresponding to their ability to perform household chores in a hypothetical situation if they did not have psoriasis. The differences indicated between the current scores and those in a hypothetical situation without psoriasis were used to define the perceived effect of psoriasis on the ability to perform household chores

Using their own words the patients were asked to list those household chores that had been particularly affected by psoriasis, i.e., no predefined list of household chores was provided and no restrictions were made as to which activities they could consider as household chores. Category groups were later constructed from an analysis of the household chores listed.

The subjects were then asked about the time they spent on general skin care, i.e. no specific or particular type of care was mentioned, by asking: How many minutes do you estimate you spent on skin care during the past week? The patients were then asked about an estimation for a hypothetical situation where they did not have psoriasis. The difference in minutes spent on skin care with and without psoriasis was calculated.

Time spent on cleaning and on laundry during the past week was assessed in exactly the same way, as well as the time the patients would have spent on these household chores in a hypothetical situation without psoriasis. The differences in times spent on cleaning and laundry related to having psoriasis was defined in the same manner as for skin care.

The patients in the following stage were asked questions about assistance: Do you get assistance for household chores from relatives or other helpers? Alternative answers being (a) no, and (b) yes, followed by: If yes, list the chores you are helped with_____. Later the household chores listed were analyzed and grouped into categories.

Subsequently the patients were asked how many minutes they received per week of outside assistance with household chores.

The necessity for additional assistance was determined by the question: Do you get enough assistance with your household chores? Alternative answers being (a) yes, and (b) no, followed by: If no, how many more minutes of help per week do you need?

The questionnaire examined, in addition to the background sociodemographic information, the number of years since psoriasis was first diagnosed and the work status.

4.2.2 Impact on leisure-time activities (II)

4.2.2.1 Patients sample

This study used the same sample as study (III) among 262 psoriasis patients. Flow chart of the sample and participation is presented in Figure 2. Also in these analyses PsA patients and those with skin symptoms only were studied as one psoriasis group.

4.2.2.2 Questionnaire

In the questionnaire (Appendix 2) the background socio-demographic information was complemented by an examination of the number of years since the psoriasis was diagnosed, work history, leisure-time activities, the time spent on leisure-time activities, how well patients were able to perform leisure-time activities; including whether the psoriasis had impelled patients to reduce or completely relinquish any activities.

Participation in the workforce was dichotomized as: 0: out of the active workforce; and 1: actively working (including students).

In their own words, the subjects were asked to list their current leisure-time activities in response to the question: List in the space below your current leisure-time activities: i.e. they were not provided with a predefined list of activities. Then, the subjects were asked how many hours per week they currently spent on the leisure-time activities in their lists: How many hours per week do you currently estimate you spend on the leisure-time activities you mentioned above? Patients were then asked to estimate: How many hours per week they would have spent on the leisure-time activities they had already mentioned in a hypothetical situation if they did not have psoriasis? The decrease in leisure-time activities caused by psoriasis was defined as the difference between the time estimated for current leisure-time activities and the estimate for a hypothetical situation without psoriasis.

A 10 cm long Visual Analog Scale (VAS) from 0 to 100, was used to assess current ability to perform leisure-time activities. On the scale 0, on the left, was labeled as an inability to perform at all and 100 on the right as an ability to perform without any difficulty. Respondents were required to: Mark an 'X' on the line which corresponds to your current ability to perform leisure-time activities with psoriasis.

In the following stage, the subjects were requested to mark an 'X' on the line corresponding to their ability to perform leisure-time activities if they did not have psoriasis, i.e. in a hypothetical situation. The difference between the scores currently and in the hypothetical situation without psoriasis was defined as the disadvantage score. The difference in the obtained scores were analyzed as group means and in quartiles.

The next question asked patients to list any leisure-time activities which had been affected by psoriasis: Have you been forced to reduce some leisure-time activities because of psoriasis? with the alternatives (a) no, and (b) yes, followed by: If yes, list them ______. The subsequent question also asked if they had been forced to give up completely some leisure-time activities because of psoriasis, again listing any activities affected. Eleven categories were then created based on an analysis of these activities. The activities were dichotomized: 0: non- sporting activities; and 1: sporting activities. They were also dichotomized as 0: activities causing no sweating; and 1: activities causing sweating. Sporting activities were defined as all those that caused sweating, and included walking. Another dichotomy was made, 0: activities with no expected embarrassment; and 1: activities where psoriasis could be considered to cause embarrassment, for example social activities and swimming.

4.3 Rheumatoid arthritis (IV)

4.3.1 Patient sample

A systematic sampling was carried out from the patient registers of the Hospital District of Southwest Finland. These registers include patients with RA treated by rheumatologists at Turku University Hospital. The patients are mostly treated in primary health care if they have a mild disease course and are thus underrepresented in this sample. The 136 patients contacted by telephone for this study interview were asked to participate in a structured telephone interview with a trained interviewer. Five patients declined to participate, and seven were unable to participate because of poor health. The final sample patient study was formed of the remaining 124 (91.2 %) patients. Flow chart of the sample and participation is presented in Figure 3. The subjects had previously given written approval as regards collection of their RA-related health data from medical records. The following sociodemographic variables were formed: age in years, number of persons in the same household analyzed as living alone or with someone, level of income calculated as household disposable monthly income per person in the household, and retirement status. The average age of the patients was 63.6 years with women comprising 69.4%, and the number of retired patients 59.0%. The mean duration of the disease was 12.5 years and the mean HAQ score 0.8.

Patients with rheumatoid arthritis treated by rheumatologists at Turku University Hospital which had participated in telephone interview about disadvantage with RA in everyday life at summer 2010 or autumn 2011 were contacted by telephone, N=136.

5 refused to participate and 7 were unable to participate because of their poor health.

124 (91 %) patients were willing to participate in the interview (autumn 2012) and formed the final study sample.

Figure 3. Flow-chart of patient selection in rheumatoid arthritis study.

4.3.2 Interview

The interviewer (research assistant) underwent training for this particular study by conducting several pilot interviews with subjects who were not included in the actual study.

The initial questions for each patient concerned their demographic background information and the number of years they had had an RA diagnosis.

In the interview (Appendix 3) the current general ability to perform household chores was assessed using a numeric rating scale (NRS) from 0 to 100, where 0 indicated an inability to perform at all and 100 as an ability to perform without any difficulty. Respondents were asked to assess, at the time of the interview, their ability to perform household chores with RA, and then to estimate their performance in a hypothetical situation if they did not have RA. The score indicating the perceived effect of RA on the ability to perform household chores was defined as the difference between the current and hypothetical scores.

In their own words, the subjects were next asked to list household chores that had been particularly affected by RA, without any prompting being provided by a predefined list. Group categories were later formed from the analysis of the reported household chores. There was no time limit on the interview required to list the chores or on the number of chores listed.

The subjects were asked to estimate the time (in hours) they spend on household chores during a week.

The following stage consisted of asking the patients whether they received assistance for household chores from relatives or other helpers because of their RA. The alternative answers being (a) no and (b) yes, followed by: If yes, list the chores you are helped with. Analysis of the household chores listed then grouped them into categories. The question was also asked as regards how many hours of outside assistance with household chores they received per week because of RA.

Additional assistance needs were determined by asking: Do you receive enough assistance with your household chores? with alternative answers being (a) yes and (b) no, followed by: If no, how many more hours of help per week would you need?

Using their own words, the subjects were then asked to list their current leisure-time activities; no predefined list of activities was given. There was no limit to the time needed to list the activities or on the number of activities listed. The following question concerned the number of hours per week the subjects currently spent on the leisure-time activities they listed. The subjects then made an estimation of how many hours per week they would have spent on the leisure-time activities they had mentioned in the hypothetical situation where they did not have RA. The reduction in leisure time caused by RA was defined as the difference between the current and hypothetical estimation of time spent in leisure-time activities.

Current ability to perform leisure-time activities with RA was assessed by NRS from 0 to 100, where 0 was labeled as an inability to perform at all and 100 as an ability to perform without any difficulty. The following part included questions on the patients' estimation of their ability to perform in leisure-time activities in a hypothetical situation without RA. The score indicating the perceived effect of RA on the ability to perform leisure-time activities was defined as the difference between the current and hypothetical NRS scores.

Patients were asked whether any of their leisure-time activities had been so affected by RA that they had been forced to decrease the time spent engaged in these activities, with the alternatives (a) no and (b) yes, followed by: If yes, please list them. They were also asked whether they had been obliged to completely forego some leisure-time activities because of RA, again by listing such activities. These activities were later analyzed and grouped into categories.

Finally, the patients were asked to complete the HAQ over the telephone by answering each of the 20 items of the questionnaire using a four-level response from 0 to 3, the higher scores indicating more disability. The HAQ score was calculated according to the suggested formula (30), producing a score ranging between 0 and 3. This corresponded to the functional ability of the patient in everyday life during the previous week.

4.4 Ethical considerations

The ethical committee of The Hospital District of Southwest Finland approved the studies of LBP (2007), psoriasis (2010) and RA patients (2007). The patients received a written description of the sampling procedure and study purpose, as well as the planned use and storage of the information they were to provide. This was followed by a description of the subject's rights according to the Helsinki declaration.

4.5 Statistical analyses

LBP study (I): The sample size was small, and the distributions of the studied variables were skewed in many cases. The statistical analyses of the data were based on $\chi 2$ test and the non-parametric Mann–Whitney U test, the Kolmogorov-Smirnov test, Fisher's exact tests and Spearman's rank correlation coefficients.

Psoriasis studies (II & III): The statistical evaluation of the data was based on Fisher's exact test and Chi-square test for proportions, and Student's t test and one-way analysis of variance for means. Pearson's coefficients of correlation were used to examine the degree of relationship between two continuous variables.

Study III: Logistic regression models were fitted to assess the impact of background variables on the likelihood (Odds ratios (OR)) of being forced to reduce or completely give up any leisure time activity, while simultaneously controlling for effects of other variables.

RA study (IV): The statistical evaluation of the data was based on a Chi-square test for proportions, a Fisher's exact test when appropriate, and a Student t test and one-way analysis of variance for means. Pearson's coefficients of correlation were used to examine the degree of relationship between two continuous variables. Logistic regression models were fitted in order to assess the impact of background variables on the likelihood [odds ratios (OR)] of being forced to reduce or completely give up any leisure-time activity, whilst at the same time as controlling for the effects of other variables. The effects were studied of the same background variables as regards the magnitudes of perceived disadvantage in household chores and leisure-time activities using linear regression models.

It was not possible, due to the relatively small sample size, to include a large number of background variables in the multivariate models. This was due to the effect of each background variable being studied in univariate models, and therefore, only those that were the most interesting and/or had significant associations with the dependent variables were included in the final multivariate models.

All statistical analyses were performed using SPSS Inc., Chicago, IL, USA, versions 20-23, and the level of statistical significance was set to $p<0.05$.

5. Results

5.1 Low back pain I

The overall disadvantage caused by LBP, including work, household chores and leisure-time activities was a mean of 21.7 when using the NRS scale of 0–100. Men reported a greater disadvantage than women in household chores and leisure-time activities. The ability to perform in any of the work, household chores and leisure-time activities was associated with an ability to perform in the others.

5.1.1 Household chores

The perceived disadvantage caused by LBP in ability to perform household chores was a mean of 30 when using the NRS scale of 0-100.

Assistance with household chores had been received by 74.4% (29/39) of the patients. The weekly average amount of help lasted 260 minutes, ranging from 15 to 840 minutes. The men had received more assistance (400 min) than the women (224 min). Age had a minor, non-significant effect on the amount of assistance received.

5.1.2 Leisure-time activities

The perceived disadvantage caused by LBP in ability to perform leisure-time activities was a mean of 20 when using the NRS scale of 0-100. Because of LBP, 82.1% of the subjects had reduced their leisure-time activities, and, out of these, 64.1% had completely given up at least one leisure-time activity. Overall, the patients had reduced the time spent doing a mean of 2.1 leisure-time activities, and had given up a mean of 1.2 leisure-time activities. The proportion of the reduction in leisure-time activities was a mean of 76.9%. The most commonly reduced were walking by 35.9% of the patients and different ball games, by 30.8% of the patients. Overall, a reduction in sporting activities was more common ($p < 0.05$) than in the other activities, and was pronounced among the men.

5.2 Psoriasis II & III

5.2.1 Household chores

In total, 19 different aspects of household chores that were particularly affected by psoriasis were identified and assigned to four different domains: physically demanding chores and those requiring manual dexterity (cleaning, gardening, holding items, handiwork, walking, moving or changing positions, dressing, lifting items), chores with skin contact with water (washing dishes, touching water, washing oneself, cooking, laundry, handling chemical substances), social intercourse and other household chores (reduced leisure-time (including the time spent on skin care), every kind of household chores, dusty chores, sleeping). Women perceived significantly more often than men that activities related to cleaning were affected by psoriasis. Otherwise, differences between sexes were small. In the same manner, household chores for which the patients received assistance were identified and assigned to three distinct categories: skin care (use of emollients, use of gauze), physically demanding chores (cleaning, vacuuming, shopping, dressing, opening a can/jar/carton removing snow/lawn raking, setting a table, lifting items) and chores with skin contact with water (laundry, washing dishes, cooking, washing oneself).

More than half of the patients (57.8%) reported disadvantage in performing household chores because of psoriasis. Among them, the mean score indicating the effect of psoriasis on the ability to perform household chores was -28.3. Almost a third (30.4%) reported that psoriasis had no impact on performing household chores and a tenth (11.8%) observed that they could perform tasks better with psoriasis. Patients with a more severe inability to perform household chores felt that the influence of psoriasis was more crucial. Recorded DLQI values were on average 10.9 (SD 8.3) and PASI values 6.4 (SD 3.9). Patients who perceived a disadvantage in ability to perform household chores because of psoriasis had significantly ($p<0.05$) higher DLQI (14.2) than those with no perceived disadvantage (7.7). There was no statistical difference in PASI values between these two groups (6.7 vs. 6.2). However, there was no statistically significant association between PASI or DLQI and the need for assistance in household chores.

Most of the patients (84.6%) reported that they had increased the time spent on skin care because of psoriasis. Patients estimated that they currently use 87 more minutes per week on skin care than if they did not have psoriasis (women 73 min and men 98 min more, NS). The average time spent on skin care with psoriasis was estimated at 116 minutes per week (ranging from 0 to 840 min) with no difference between sexes. A quarter of the patients (27.4%) had increased the time they spent cleaning and 15.3% had increased the time spent on laundry because of psoriasis. The overall amount of time spent performing cleaning and laundry when having psoriasis was estimated at 107 minutes and 66 minutes per week, respectively, with a significant difference between sexes for laundry (women 108 min and men 35 min, $p<0.05$). On average, cleaning was performed for 4 minutes more per week and laundry 3 minutes more per week because of psoriasis.

Because of their psoriasis, more than a quarter (28.0%) of the patients received assistance with household chores, including skin care. For these patients, the average duration of assistance received was 91 minutes per week: 123 minutes for women and 64 minutes for men ($p < 0.05$). The need for more assistance with household chores was reported by 20.9 % of the patients with psoriasis, women significantly more often than men.

The impacts of patients' age, the duration of the disease and work status were marginal and statistically non-significant in all analyzed characteristics of psoriasis and household chores.

5.2.2 Leisure-time activities

The grouping of affected leisure-time activities listed by respondents produced the following categories: walking (n = 17), social activities (n = 15), intellectual or spiritual or mental activities (n = 14), those requiring manual dexterity (e.g. knitting) (n = 10), running (n = 6), ballgames (n = 18), gymnastics (n = 7), swimming/diving (n = 91), dancing (n = 3), cycling (n = 5), muscle exercise/body building (n = 17).

More than half of the patients (51.9%) had either reduced or completely given up at least one leisure-time activity. Almost a third of the patients had been forced to reduce at least one leisure-time activity. Patients in the active workforce had reduced leisure-time activities more often than those who were out of the active work-force. A third of the patients had been forced to give up completely at least one leisure-time activity. Women had given up leisure-time activities slightly less often than men (NS). Nearly half of the patients (44.6%) who had been forced to reduce leisure-time activities had also been forced to give up at least one leisure-time activity. Years with psoriasis diagnosis, PASI and DLQI values had minor and non-significant effects on the likelihood of having reduced or completely given up leisure-time activities.

The overall amount of time spent performing leisure-time activities was estimated at 830 minutes per week (741 min for women and 898 min for men, NS). The average overall reduction in time spent on leisure activities because of psoriasis was 91.7 minutes per week. Women had reduced the time spent on leisure time activities by a mean of 129 minutes per week and men by a mean of 64 minutes per week (NS). A quarter (23.7%) of the patients felt that they would spend more time on leisure-time activities if they did not have psoriasis, 71.0% would spend the same amount of time and 5.3% reported that they would spend less time on leisure-time activities if they did not have psoriasis. Some patients reported that psoriasis had given them new opportunities to work as volunteers, for example with psoriasis associations or social occasions for people with psoriasis. The mean disadvantage score attributed to psoriasis on performing leisure-time activities was 16.9. The difference between men and women was 4.0 (NS). Younger age was associated with greater disadvantage in leisure-time activities ($r = 0.154$, $p<0.05$). The quartile of patients reporting the most marked disadvantage was significantly ($p<0.01$) younger (mean 52.6 years) and had a higher ($p<0.01$) DLQI value (16.5) than the others (59.8 years and 8.8, respectively). The effects of disadvantage of years having a psoriasis diagnosis and PASI values were minor and non-significant.

In logistic regression models, increasing age decreased the likelihood of having been forced to reduce any leisure-time activity but not the odds of giving up completely. However, a prolonged duration of psoriasis significantly increased the likelihood of being forced to give up completely a leisure-time activity, but had no impact on the likelihood of reducing leisure activities.

Those who reported a reduction in sporting activities due to psoriasis were significantly ($p<0.01$) younger (mean age 53.0 years) than respondents who did not reduce sporting activities (mean age 60.1 years). Those who reported a reduction in activities causing embarrassment were significantly younger than those who did not reduce these activities (54.4 years vs. 59.5 years, $p<0.05$), with a similar finding for activities causing sweating (53.8 years vs. 60.1 years, $p<0.01$).

5.3 Rheumatoid arthritis IV

Most of the studied background variables such as age, years with RA diagnosis and retirement status had minor and nonsignificant association with the odds of disadvantage performing household chores or having given up or reduced leisure-time activities.

5.3.1 Household chores

In total, 59 different domains of household chores that were particularly affected by RA were identified and assigned into 16 different categories: cleaning, working with hands, vacuuming, cooking, heavy duty, lifting items, opening a can/jar/carton, carrying items, general moving/positions, rug beating, walking, washing oneself, window cleaning, reaching above shoulders, floor cleaning/brushing, and other household chores. Most of the household chores mentioned were related to cleaning of the house. Eleven of the categories were similar to those included in the HAQ index. In the same manner, household chores for which the patients received assistance were identified and assigned to nine distinct categories: cleaning, heavy duty, rug beating, shopping, cooking, vacuuming, window cleaning, every kind of household chores, and other household chores. Most of the household chores patients mentioned were physically demanding.

The overall mean score indicating the effect of RA on the ability to perform household chores was −25.5, with minor (NS) difference between sexes. The majority of the patients (84.6 %) reported disadvantage in performing household chores because of RA. For these patients, the mean score indicating the effect of RA on the ability to perform household chores was −30.1.

More than half of the patients (55.7 %) received assistance with household chores, women significantly more often than men (69.0 vs. 26.3 %, $p < 0.01$). For these patients, the average duration of assistance received was 6.2 h per week: 5.1 h for women and 13.7 for men ($p < 0.05$). However, out of the men receiving assistance, two received 30 h per week, skewing the distribution. The need for more assistance with household chores was reported by 10.4 % of the patients with RA, and they all were women.

5.3.2 Leisure-time activities

Leisure-time activities listed by respondents as affected by RA were grouped into seven categories: running, cycling, gymnastics/muscle exercise/swimming, other sport activities, walking, those requiring manual dexterity (e.g., knitting), and other activities. These were mostly related to sport. The majority of patients (77.2 %) had either reduced (60.5 %) or completely given up (61.3 %) at least one leisure-time activity. The mean score indicating the effect of RA on the ability to perform leisure-time activities was −20.5, with minor (NS) difference between sexes. No patients reported improved ability to perform leisure-time activities with RA.

The overall amount of time spent performing leisure-time activities was estimated at 12.4 h per week. The average overall reduction in time spent on leisure activities because of RA was estimated at 1.5 h per week (women 1.7 h and men 0.6 h per week, NS). One-third (37.3 %) of the patients felt that they would spend more time on leisure-time activities if they did not have RA, 57.8 % would spend the same amount of time and 4.8 % reported that they would spend less time on leisure-time activities if they did not have RA.

In logistic regression models, a higher HAQ score was significantly associated with higher odds of being forced to reduce and to completely give up leisure-time activities, and with higher odds of receiving assistance in household chores. Women had higher odds than men to have reduced leisure-time activities. In linear regression models, a higher HAQ score was significantly ($p < 0.01$) associated with more perceived disadvantage in household chores and leisure-time activities. Age and/or years with RA diagnosis had minor and nonsignificant effects in all regression models.

6. General discussion

6.1 Sampling and methodology

The three samples used in this study were all drawn systematically from the patient registers of the Hospital District of Southwest Finland. Systematical sampling was not expected to cause any selection bias. The first study was comprised of patients who had been referred to the Department of Physical and Rehabilitation Medicine, at Turku University Hospital with a primary cause for referral being non-specific chronic low back pain (LBP). The time frame of 6 weeks for determining LBP as chronic was used because at the time of the study primary health care physicians were adviced that non-specific LBP patient referral to Department of Physical and Rehabilitation Medicine at Turku University Hospital should take place only after the patient had symptoms for minimum of 6 weeks. Referred patient did not need to have any more specific diagnosis or such done by clinical specialists. However, infections, traumas, and malignancy as the cause of LBP were used as exclusion criteria, because these were expected to cause misinterpretations to overall findings and the studied patient group would not have been homogenous enough.

This study employed qualitative approach and interview methodology using open ended questions, which were later categorized by the authors of the study. The nature of the methodology did not allow large sample sizes, which could be obtained when using e.g. mailed questionnaire forms. In studies using interviews with open answering options the sample size is usually relatively small. Because of the used methodology and the sample size this LBP work could be considered as a pilot study. Based on its findings quantitative studies with larger sample sizes could be planned.

The data for the psoriasis study came from a larger survey, where the burden of psoriasis was evaluated from various points of view. The economic consequences and influence of psoriasis on the ability to work have been reported in two earlier theses (2,18) utilising the same survey data. In addition, the sampling of the psoriasis study patients was based on the patient registers of the Hospital District of Southwest Finland. The psoriasis study patients were those treated by specialists in the Department of Dermatology, at Turku University Hospital. Those patients with skin symptoms only and patients with both skin symptoms and arthritis were analyzed as one psoriasis group, because there were no statistically significant differences in any of the analyses conducted between these two patient groups. One reason for non-significant differences may be that the number of PsA patients was only 35. With larger sample sizes some studied comparisons may have turned out to be statistically significant.

The third patient sample was based on patients who had been treated in the Rheumatology Clinic of Turku University Hospital. These patients had participated earlier in questionnaire and interview studies dealing with the perceived disadvantages of rheumatoid arthritis (RA). Because they had participated in earlier studies and had given their consent to also participate in later studies, they can be considered a selected RA population. Their earlier consent most probably affected positively the participation rate in this study.

Because all the study patients came from patient registers of the Hospital District of Southwest Finland, some caution should be employed when generalising the findings of these studies. However, the patients as subjects and the symptoms of their disease hardly differ from those of other Finnish patients with same diagnoses. Nevertheless, the availability of services and the clinical care provided in the Hospital District of Southwest Finland may be different from other parts of the country, which may have an impact on how the patients perceive their disease to influence their everyday life. However, the influence of the geographical area of sampling can be expected to be minor.

In the Finnish health care system, patients with mild symptoms or a disease in remission status are usually treated and followed-up in primary health care. Only moderate and severe disease manifestations are referred to, treated, and followed-up in tertiary level hospitals, such as Turku University Hospital. Thus, the patient samples in this study do not represent all the patients with these diseases, but can be considered to better represent those with at least a moderate level of symptoms or disease status. This can be expected to increase the probability of occurrence and significance of the reported burden.

In the LBP and RA studies, an interview method was employed for data collection. This takes more time and is otherwise a more resource demanding method than utilising a questionnaire. However, with the interview method, more detailed information can be collected and the interviewer has an opportunity to clarify unclear points, in case the interviewee does not understand the question directly. The interviewer explained to all participants that the time for answering was not limited at all. However, in a telephone interview situation the respondent may not be willing to spend a long time recalling answering alternatives.

The interviews in LBP and RA studies were carried out by two individuals, both trained for the task. LBP study interviews were carried out by the author and those in RA study were carried out by a research assistant who was not a member of the actual research team. Due to practical issues it was not possible to employ the author to carry out RA interviews and outside assistance was necessary. However, this was not expected to produce any significant bias. It is very common to have more than one interviewer to carry out interviews, and the interviewer in RA study was trained and experienced. This research assistant had been conducting several interviews in other studies comprising RA patients. Her experience and previous knowledge of RA patients' symptoms can be expected to increase the reliability of the collected data. In both studies the author or research assistant conducted all the interviews and all the questions were asked in the same order and in the same manner. Moreover, in both studies the interviewer performed pilot interviews with subjects who were not among the actual study samples. These pilot interviews helped to modify and standardise the manner of asking the questions. This preparation was expected to reduce the possibility of an interview bias, where any variance in interviewing can produce systematic error in the data.

As stated earlier, the psoriasis study was part of a larger survey, which employed a questionnaire method. The questionnaire form included a large number of questions, from the many aspects of everyday life that could be affected by the disease. It was not considered feasible to try to collect all the required information through interviews. When the questionnaire forms were sent to sample patients, they had the opportunity to give their answers when they consider it convenient. In addition, they also had the opportunity to complete the questionnaire when convenient as they could give answers to some questions at one time and continue later with others. The patients also had more time to recall their answers, when they had had the opportunity to return to the questions later. However, when employing the questionnaire method, the researchers and respondents do not usually have contact so that unclear points about the questions can be clarified. In order to provide the possibility to ask about unclear points a telephone number was provided with the questionnaire form for enquiries; however, the phone calls by respondents were very few.

Despite the differences in original samples and data collection methods between the three studies most of the questions the patients were asked about household chores and leisure-time activities were similar. The number of questions and formulation of phrasing was determined by the disease in question in each of the studies. Thus, several data analyses could be done in a similar manner, which allowed some comparison of the findings. However, due to the different nature of the diseases and their symptoms, direct comparison between the diseases and these study findings should be done very cautiously. It would be interesting to learn how much the chosen method of data collection affects the findings of this type of study. However, such method testing is out of the scope of this thesis, and would require a completely different type of study settings.

The symptoms of a chronic disease and their severity vary over time. Patients with the same or similar clinical disease status may experience it very differently. In addition, disease severity may vary over time and the same patient may perceive the burden of the disease differently, depending on their general life situation or experiences. Some patients had experienced slowly deteriorating symptoms over decades, or had had the disease all of their lives, whereas some others had experienced a more rapid worsening, or had developed the disease recently. To minimize the effects of symptom variation and recall bias, the time frame 'currently' was used in these studies, when the patients were asked to evaluate the influence of the disease. However, when the respondents assessed their ability to perform household chores or leisure-time activities without the disease, it was not meant to mean the time before the disease started. This was because although this may have been possible to recall for those with a recent onset of symptoms, it might be impossible to recall for those with a long disease duration, or a lifelong disease experience. Thus, the use of a hypothetical situation without a definite time frame was thought to decrease the variance a possible recall bias might cause.

Most of studied background variables, such as the patients' age and the duration of the chronic disease had minor or non-significant associations with the disadvantage perceived in performing household chores or having to give up or reduced leisure-time activities. This is probably because of the relatively high mean age of the participants in the present study samples. Disease duration and the development of comorbidities may also be relevant to outcome measures and their priorities. Early in the disease process, some symptoms may be almost unrecognised, or they may be experienced so strongly that they control the patient's whole life. During active working life, a disability at work may be highly relevant, whereas for a retired person the ability to work has clearly less significance. Later in the disease process there are usually additional matters to consider, such as comorbidities and toxicities from prolonged use of medication.

6.2 Concepts of household chores and leisure-time activities and methods to solicit information on them

The definitions of household chores and leisure-time activities are ambiguous in LBP, psoriasis, and RA literature, which makes comparison of the study findings difficult or sometimes even impossible. In one hand, the concept of leisure comprised a wide spectrum of categories, like problems in public places, going out socially, sports, and habits such as smoking and drinking (105). On the other hand, leisure activities were stated to include physical activities, which were described as also covering occupational activities (109). Many sort of activities were found in outdoor activities as including items such as sporting activities, walking, sunbathing on the beach, going to the hairdresser, and choosing and buying clothes (109). In a US study (101), the concept 'activities of daily living' was stated to include more specific functions such as using hands, walking, sleeping, sitting, standing for long periods, and performing work duties, but it did not contain any specific leisure-time activities, which could also be considered a part of daily living. The literature dealing specifically with household chores and/or leisure time activities is limited. Considerably more studies would be needed. Good example of this scarcity is the fact that during recent years no other journal articles spesifically focusing on these issues could be found except those of the author and coworkers.

In the present study, the open-ended questions on household chores and leisure-time activities were not predefined by the researchers or clinicians, but the patients determined themselves which activities they wanted to consider as belonging to these concepts specially affected by their chronic disease. This could be considered as strength in this thesis. Patient-specific approach has been stated to be able to detect changes that were highly relevant for the individual patient (190). A wide range of instruments have been developed to measure the pain and disability of patients with LBP, psoriasis, and RA (30,51,76). In most cases, health care professionals have not experienced the disability patients with chronic disease face at home and in everyday life (191). In most studies dealing with burden of diseases health care professionals define the concepts patients are asked (192). Also they usually define the categories of the severity of each concept. In such studies some concepts that are crucial to patients may be omitted and some included concepts may be irrelevant to patients, but they would have chosen them because the correct concept would not have been available to them. This could be expected to be pronounced in cases when ready-made lists of concepts were developed in one society and used in another. Thus, allowing patients to describe with their own words where they feel their disease is causing burden to them can be expected to give a more comprehensive picture of the burden. Most important outcome markers for patients have been found to be functional tasks that affected their daily living (193). The method of open-ended questions probably produced concepts of household chores that more accurately reflected the household chores most relevant to the everyday lives of patients with the chronic disease, as well as activity concepts that precisely reflected the leisure-time activities actually enjoyed by the patients.

A patient-specific approach has been considered to have potential for use as an outcome measure, both in clinical trials and in daily practice (142,194-197). The communication about the disease burden of a chronic disease between patient and health care provider is critically important in management of optimal care and achievement of treatment goals (6,160). The importance of a patient-oriented approach has been emphasised when assessing RA patients' physical functioning and mobility. The shortcomings of the most commonly used functional measure among RA patients, the Health Assessment Questionnaire (HAQ), which is solely based on items deemed important by health care professionals, became obvious in the study, where 75% of the patients named at least one impaired activity from the category 'mobility', and only 48% of these activities were covered by HAQ items.(141) The majority of the household chores listed spontaneously were also represented in the 20 items of the HAQ, but this measure included very few of the listed leisure-time activities, which has been also observed in other studies (160,198). However, in the present RA study, a higher HAQ score was significantly associated with a higher probability of being forced to reduce and to completely give up leisure-time activities, and with a higher probability of having to receive assistance in household chores. It seems that, even with these shortcomings, the HAQ measures give a reasonably good overview of the patient's perceived disadvantage of having RA when performing household chores and leisure-time activities.

A scale from 0 to 100 was used for measuring the perceived performance of household chores and leisure-time activities with a chronic disease. For most people a scale from 0 to 100 was thought to be easy to comprehend. People are used to thinking in percentages, especially as the currency we use every day is divided into 100 units.

In many studies focusing on patients' quality of life (QOL) also household chores and leisure time activities have been included. However, these two areas of everyday living have not been particularly emphasized in them, but the focus has been on the overall QOL. In most cases it was not possible to separate the role and magnitude of household chores and leisure time activities from the QOL measurements. In those few cases when household chores and/or leisure time activities were possible to be determined the studies were included in this thesis. Current thesis concentrates on household chores and leisure time activities, and including QOL literature or measurements used in studying it would have taken the focus of this work away from the two main concepts of interest.

6.3 Many forms of burden of three chronic diseases on household chores and leisure-time activities

All of the disease groups studied have specific symptoms which require attention. Psoriasis patients have to devote extra time for skin care thus making it different from LBP and RA. LBP patients may need to have active physical exercise sessions more often than psoriasis and RA patients, and joint destruction, which is often related to RA, affects a whole variety of functions related to body movements.

Household chores and leisure-time activities have an important role in our lives and usually are an important part of everyday life. Impairment in these activities can have a negative impact in various ways. This study's findings show that the influences of those chronic diseases on the performance of household chores and leisure-time activities are mostly negative. All four articles of this research work have indicated that the level of the overall disadvantage caused by those three chronic diseases is significant, although not necessarily dramatic. Using the "current ability to perform minus perceived ability in a hypothetical situation without the disease" as the deduction formula employed to measure the magnitude of the burden in household chores, this would suggest that LBP patients experienced slightly more disadvantage in household chores than RA patients, and twice that of psoriasis patients. In leisure-time activities, however, the differences were smaller as was the magnitude of the burden perceived. However, direct comparison of these figures is not justified, not least because there were differences in the methods of acquiring this information from the patients. LBP and RA patients gave their performance estimates during a telephone interview and psoriasis patients completed questionnaire forms.

The magnitude of disadvantages varied between the diseases, as did their manifestations. Chronic disease can cause various problems for the patient and the specific characteristics of each disease makes the burden different compared to other diseases. LBP and RA patients perceived the physical handicap as the most burdensome, but stigmatization and esthetic problems did not have same importance as they had among the psoriasis patients. Psoriasis is often a highly visible disease, e.g., with lesions on the scalp, neck and hands, and this could cause embarrassment or shame, and changes in the patients' social behaviour. Feelings of shame due to psoriasis can have a strong impact on social life, since they can result in the avoidance of public places, thus reducing social opportunities (108). These feelings may also have a potential impact on employment and relationships. The burden of stigmatization could be expected to be emphasised more by women (199). However, this study sample did not corroborate such a conclusion. It may be that stigmatization is a burden that is strongly dependent on the prevailing culture and outlook expectations in society.

All three chosen diseases are chronic in nature and currently there is no cure for any of them. This similarity was the reason for choosing these diseases to represent the whole variety of chronic uncurable diseases. Although the aetiology and symptoms of the diseases are different the study demonstrated the variety of disadvantage patients experience in both household chores and leisure-time activities when living with a chronic disease. This study findings also clearly demonstrated how important it is to have a disease specific approach when planning to estimate the disadvantage caused by any chronic disease.

The burden of chronic disease affects not only the patient but also the patient's relatives and other close individuals. The study findings suggest that when patients with chronic disease receive adequate treatment the beneficiaries are also those in a close relationship with the patient. This corroborates the earlier findings of Eghlileb et al. (3) that psoriasis patients' relatives and partners experience a deterioration in their close and intimate relationships due to the fluctuation in the attitude or mood of psoriasis patients. In addition, they found that caring and helping patients with psoriasis and the time required for those activities negatively affected the performance of household chores and leisure-time activities of relatives and partners (3). There are no similar studies conducted among patients with LBP or RA, but such research would increase our understanding of the magnitude of the burden chronic diseases cause in society. It would not be justified to assume that the relatives and other helpers of LBP or RA patients would feel and react similarly to those closely related to psoriasis patients. Studies among those close to LBP and RA patients could reveal a completely different picture.

6.4 Chronic disease and performance in household chores

This thesis shows that the role of household chores in coping with everyday life is considerable, and chronic disease seems to have a significant negative impact on their performance. Because of the disease, one may need to carry out household chores with more precautions in order to avoid pain or other discomfort. The use of different types of adaptive aids and devices may ease the performance, however, it is possible that at the same time they can make the performance more complicated, as indicated by Allaire et al. (32). They showed that patients with RA had lowered their standards of cleaning and cooking, included the use of adaptive aids, and modified their work methods (32). It may even be possible that performing household chores becomes completely impossible because of the chronic disease. At any stage of disease development, the patient may be forced to ask for assistance from others. Adaptive aids, helping devices, and outside assistance may all create an economic burden on the patients and their families. Furthermore, it is important to keep in mind that increased time spent on household chores may also reduce the disposable time that can be spent on enjoyable leisure-time activities.

Many of the functions where the patients in this study experienced difficulties performing properly were related to cleaning the house, particularly those tasks that required physical strength. The average age of the patients in all the study samples was relatively high, which may overstress the role of those three chronic diseases on the performance of physically demanding tasks. Younger patients probably manage to do tasks that require physical strength better than the elderly. Samples with larger proportions of younger patients would probably produce a list of tasks that would not include all those that arose in these studies, and the relative occurrence of the tasks would probably also differ. Added to the functions requiring physical strength in their performance, psoriasis patients also reported problems in those demanding manual dexterity or skin contact with water. Skin lesions may be irritated by contact with water and psoriasis patients may need to clean skin flakes from the floor or wash clothes more often.

Some psoriasis patients reported performing household chores better with their disease than without it. This may be the result of having adapted well to living with their disease. In addition, they may have succeeded in developing working methods that help them to perform household chores despite the symptoms of the disease. Despite the fact that the questions were based on a similar questionnaire that had been used among rheumatoid arthritis patients earlier (157), and they were piloted among patients before use, there is still a possibility that some respondents misunderstood the questions. However, the role of such a source of bias cannot be determined.

Assistance with household chores was most often requested by LBP patients, followed by RA patients, and clearly less often for psoriasis patients than the two other groups. The LBP sample was small and contained probably more severe cases than the two other patient groups. The LBP patients were referred to a specialist clinic, which indicates that their LBP symptoms were so severe that primary health care considered them to need specialist care. RA and psoriasis patients, on the other hand, had been in specialist care and follow-up and it can be assumed that in many cases their treatment had reached successful outcomes. However, as a whole, it seems that psoriasis patients needed assistance less often for household chores and the assistance time needed also seemed less for psoriasis than LBP and RA patients. The symptoms of psoriasis do not probably cause as much of physical handicap as LBP and RA.

Women with psoriasis received significantly more assistance time for household chores than men, but women with LBP and RA were reported as receiving less than men. One reason for the observed difference could be the different nature of the diseases. Psoriasis patients received assistance particularly in those household chores including skin contact with water. In general women do more household chores than men, including also those with skin contact with water. In many cases, women received assistance in physically demanding household chores. By nature, men are stronger than women, which may explain why women needed assistance more often. Furthermore, as women’s role at home may include more housekeeping tasks than men’s, it is understandable that women with chronic disease may need assistance more often than men. It seems that a chronic disease does not produce a gender neutral burden as regards household chores.

Although a large number of patients received assistance in household chores from relatives or other helpers, the assistance was not always considered sufficient. The need for additional assistance was pronounced among women. There is obviously a hidden need for more assistance with household chores, which suggests that the estimates in the present study of the burden created by these diseases are probably underestimates.

6.5 Chronic disease and performance in leisure-time activities

Pleasure producing leisure-time activities can be considered an important part of every person's life, including those suffering from a chronic disease, and they are essential to achieve and maintain physical, psychological, and social well-being. The impact of three chronic disease on patients' everyday life is well demonstrated by this study's findings that more than half of the psoriasis patients and up to four fifths of the LBP and RA patients had either reduced or completely given up at least one leisure-time activity. The psoriasis study sample was comprised of patients with relatively well-managed psoriasis, which could partially explain the lower frequency of reducing or give up leisure-time activities. In earlier studies (105,109-111), the prevalence of psoriasis patients whose physical, social and other leisure-time activities were affected seems to vary according to the severity level of the psoriasis, and depend on the definitions of leisure-time activities.

Despite the fact that the literature on the influence of RA on performance of household chores and leisure-time activities is far more extensive than that concerning LBP or psoriasis, there are relatively few studies reporting the proportions of patients whos' RA had affected their performance of leisure-time activities. In one study (165), three-quarters of the RA patients had been forced to alter leisure-time activities and in another (36) one-third had reduced their participation in LTPAs during preceding year. Negative effects on performing leisure-time activities have been reported varying from by more than half of the RA patients (159) up to almost every patients in the study (13). However, all these results are relatively well in accordance with the present study findings, which supports the reliability of the findings.

Although a relatively high proportion of the patients with a chronic disease are forced to reduce or completely give up at least some leisure-time activities, while others may take up new leisure-time activities. Some may also modify their style of performing activities to allow them to maintain their customary leisure-time activities (160,168). While others may be able to continue the activity with less intensity, instead of being forced to totally stop. Social contacts and social support may be maintained if the disease does not completely prevent the patient from performing leisure-time activities. However, being forced to completely give up activities, which are important in maintaining social networks, may increase the risk of losing such contacts. On the other hand, new leisure-time activities may bring new social contacts.

Gender differences as regards the impact of a chronic disease was demonstrated well in the psoriasis study, which showed that the women tended to reduced or give up leisure-time activities less often than men, but that their overall reduction time was longer. This might be because the women were involved in more time-consuming leisure-time activities than men. Men had both reduced and given up sporting activities more often than women. The men had probably performed these leisure-time activities with a higher intensity, as they had reduced the time they allocated to sporting activities less than women. Reducing sporting activities can lead to a gradual deterioration in a patient's physical condition, and this was probably experienced more often by the men. There is some evidence that male patients with LBP experience deterioration in aerobic fitness more often than female patients (14).

At a younger age people tend to be more involved in physical exercise, and in the psoriasis study a younger age was associated with a greater disadvantage in leisure-time activities. Again, relatively high mean age of the respondents in all three patient samples may have cause a bias in the results. Older patients may have fewer physically active leisure-time activities to reduce or give up than younger patients, and thus, with the age distributions of these samples, the findings can be considered to have produced conservative estimates.

Few decades ago common opinion was that physical activity was not recommended for patients with LBP or RA. However, current opinion contradicts this assumption and instead of avoiding physical activity, it is recommended in most cases. Regular physical activities can be expected to improve aerobic fitness. A lower level of aerobic fitness may further promote the experience of being disadvantaged among chronic disease patients, and predispose them to other disabilities.(40,200)

The subjects with LBP or RA rarely mentioned any social, intellectual, spiritual, or mental activity that they had been forced to reduce or give up. This was different from the findings from the patients with psoriasis. This difference might be due to different manifestations of the diseases. LBP and RA have a greater impact on the ability to move, while the feeling of being stigmatised may play a more significant role in psoriasis.

A small proportion of psoriasis and RA patients reported that they spend more time on leisure-time activities with the disease than they would have spent without it. Patient associations offer many types of leisure-time activities and some of the patients may have been prompted to take part in these. Patient associations provide an excellent forum for peer contacts and some patients mentioned that they had found new activities and friends through these associations.

7. Conclusions

The perceived disadvantage caused by LBP in ability to perform household chores was a mean of 30, when using the scale from 0 to 100. More than half of the patients with psoriasis reported difficulties in performing household chores because of the disease, with physically demanding tasks and those involving contact with water mentioned most often. Patients estimated that they currently use about 1,5h more time per on skin care than if they did not have psoriasis. Among the patients with RA, a disadvantage in household chores was perceived by over four-fifths; with the difficulties affecting a wide range of everyday household activities, and tasks related to house cleaning being mentioned most often. It had been necessary to organize assistance with household chores, because of their disease for three-quarters of the patients with LBP, a quarter of those with psoriasis, and for more than half of the RA patients. Fifth of the patients with psoriasis and tenth of RA patients reported the need for additional assistance with household chores. Four-fifths of the patients with LBP reported that they had had to reduce or completely give up at least one leisure-time activity because of the LBP, and this disadvantage was most pronounced among sporting activities. More than half of the patients with psoriasis had either reduced or completely given up at least one leisure-time activity because of the disease; those most often mentioned were swimming, ballgames, walking, and social activities. Among RA patients, a reduction or a giving up of leisure-time activities was reported by over three-quarters, with activities related to sport being the most affected.

All three studied chronic diseases seem to have significant negative impact on patients' ability to perform household chores and leisure-time activities, which are an important part of everyday life. This influence can produce a physical, psychological, emotional, and social burden on patients and reduce their quality of life. Manifestations of the chronic diseases as well as many of the patient's characteristics, such as age, gender, and the experienced disease duration determine the household chores or leisure-time activities that are affected, and the strength of this influence. The findings of this study suggest that, at least in the case of the three chronic diseases selected, physically demanding tasks were those where patients most often perceived disability. The burden of chronic disease is not only on the patients, but it can strongly affect the lives of partners, relatives and other close friends. The need for assistance from relatives and other helpers in performing household chores can be considerable, and the findings suggest that the patients do not receive as much outside help as they deem necessary.

Although the importance of having a satisfying leisure-time is widely acknowledged, it is an area of medical research that has been largely neglected. In the future, it would be important to recognise the whole variety of burdens chronic diseases cause in everyday life. This should be recognised both in the research and in clinical patient treatment. Research protocols aiming at investigating the burden of diseases should not only concentrate on the clinical symptoms and the impact on work productivity or other economic consequences. Concentrating on economic and productivity consequences may underestimate the complex impact of the disease. Patients with a chronic disease live with it all day every day and a significant proportion of this time is spent in dealing with household chores or in leisure-time activities. A holistic approach to patient treatment would undoubtedly benefit from careful consideration of how the disease status affects the patient's ability to cope with everyday activities. Successful treatment outcomes should not be evaluated only through assisting the patient to return to the active workforce, and more emphasis should be placed on the patient's ability to run ordinary everyday activities at home and in hobbies. By doing so, it might be possible to gain more in-depth knowledge about the overall impact the chronic disease has on patients' lives.

More research is needed to determine the most essential daily activities where patients with different chronic diseases face the most difficulties. The lists of items produced by health care professionals have been shown to include several tasks which have minor importance to the patients. At the same time, such lists lack many of the tasks which the patients perceive as important and where they have most difficulties. It would be important to compile a measurement tool that includes the most commonly occurring disadvantages, and at the same time, gives a relative weight reflecting the magnitude of the effect of those events that occur the most often. Those tasks, which occur most often together with their perceived disadvantages, are best determined by the phrasing and expressions used by the patients themselves. Applying open-ended questions can reveal new factors and associations that may remain undetected if only answers determined by professionals are offered.

The findings of this study can help to form a more comprehensive picture of the multiple and extensive influence chronic diseases have on patients' everyday life. It is important to recognise the whole diversity of disadvantages chronic diseases can cause. Because all daily activities are not equally important to people, it is important to be able to identify and measure which actions are perceived more significant than others. Among those that patients perceive as important are the many everyday activities that belong to household chores and leisure-time activities. Including such activities as part of the goal of the treatment of a chronic disease would generate more comprehensive approach when estimating the benefits for the patients and aiming to optimal care of a chronic disease.

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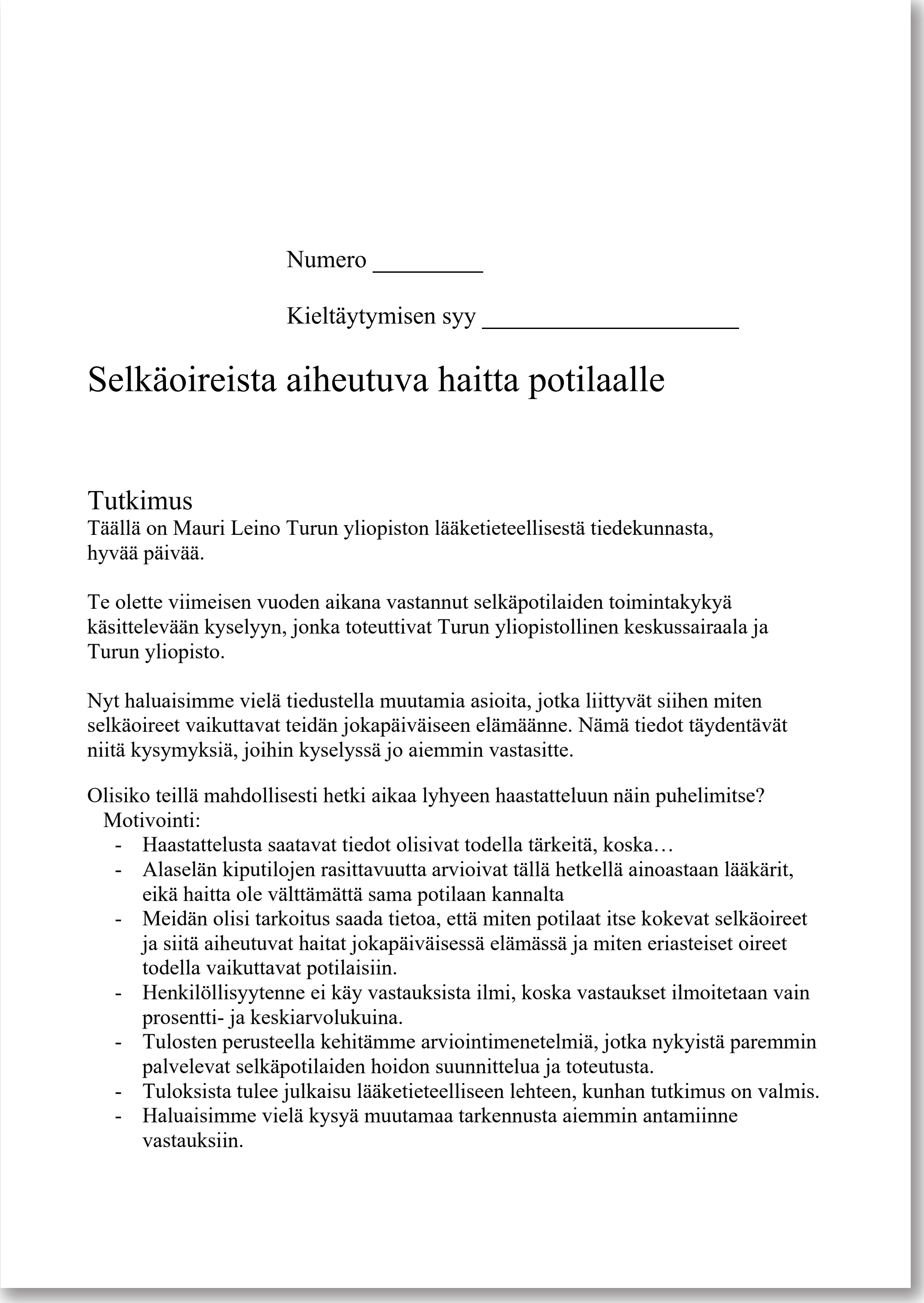
10. Appendices

Appendix 1.



Numero _________

Kieltäytymisen syy _____________________

Selkäoireista aiheutuva haitta potilaalle

Tutkimus

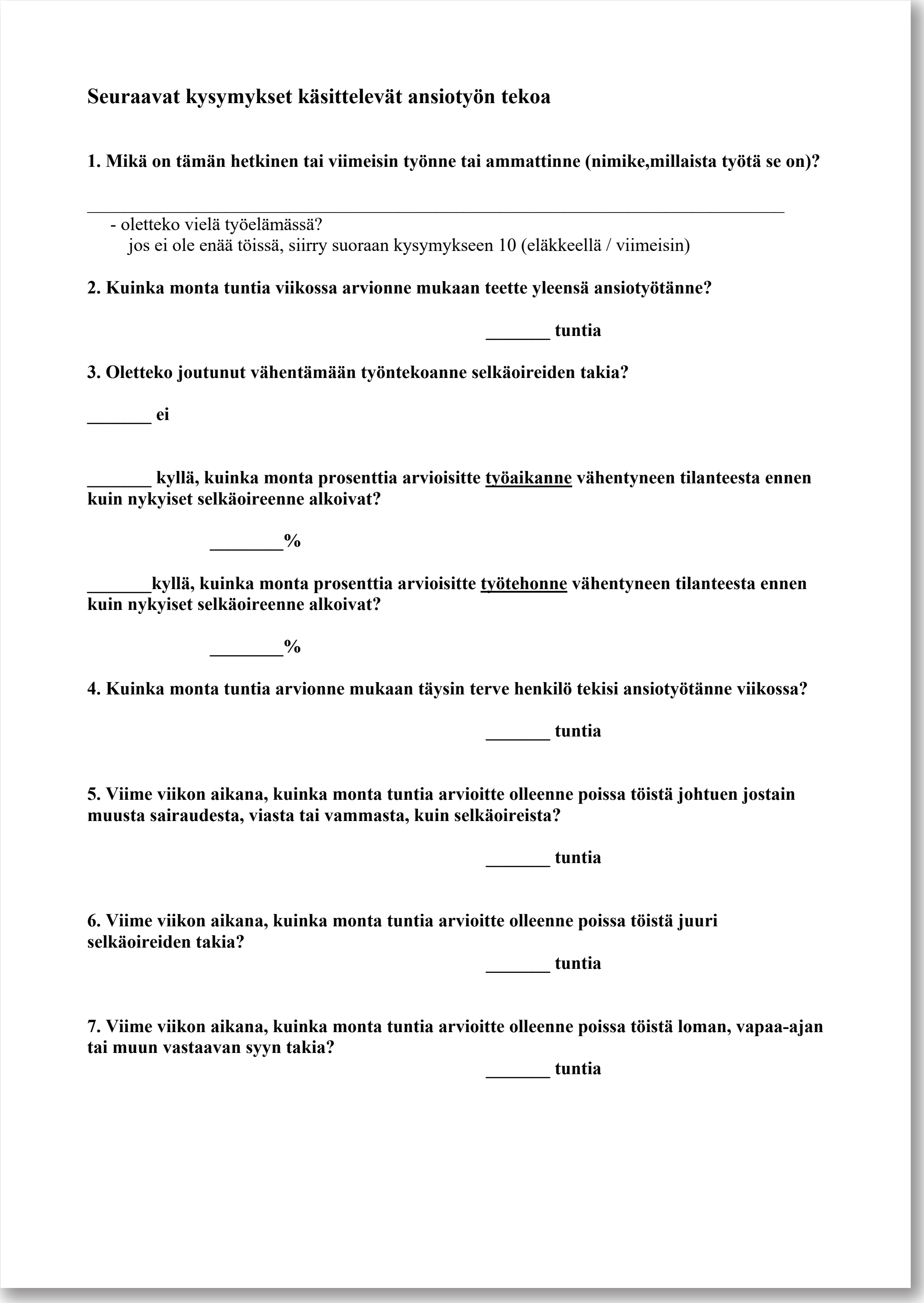
Täällä on Mauri Leino Turun yliopiston lääketieteellisestä tiedekunnasta,
hyvää päivää.

Te olette viimeisen vuoden aikana vastannut selkäpotilaiden toimintakykyä käsittelevään kyselyyn, jonka toteuttivat Turun yliopistollinen keskussairaala ja Turun yliopisto.

Nyt haluaisimme vielä tiedustella muutamia asioita, jotka liittyvät siihen miten selkäoireet vaikuttavat teidän jokapäiväiseen elämäänne. Nämä tiedot täydentävät niitä kysymyksiä, joihin kyselyssä jo aiemmin vastasitte.

Olisiko teillä mahdollisesti hetki aikaa lyhyeen haastatteluun näin puhelimitse?
Motivointi:

- Haastattelusta saatavat tiedot olisivat todella tärkeitä, koska…
- Alaselän kiputilojen rasittavuutta arvioivat tällä hetkellä ainoastaan lääkärit, eikä haitta ole välttämättä sama potilaan kannalta
- Meidän olisi tarkoitus saada tietoa, että miten potilaat itse kokevat selkäoireet ja siitä aiheutuvat haitat jokapäiväisessä elämässä ja miten eriasteiset oireet todella vaikuttavat potilaisiin.
- Henkilöllisyytenne ei käy vastauksista ilmi, koska vastaukset ilmoitetaan vain prosentti- ja keskiarvolukuina.
- Tulosten perusteella kehitämme arviointimenetelmiä, jotka nykyistä paremmin palvelevat selkäpotilaiden hoidon suunnittelua ja toteutusta.
- Tuloksista tulee julkaisu lääketieteelliseen lehteen, kunhan tutkimus on valmis.
- Haluaisimme vielä kysyä muutamaa tarkennusta aiemmin antamiinne vastauksiin.



Seuraavat kysymykset käsittelevät ansiotyön tekoa

1. Mikä on tämän hetkinen tai viimeisin työnne tai ammattinne (nimike,millaista työtä se on)?

____

- oletteko vielä työelämässä?
jos ei ole enää töissä, siirry suoraan kysymykseen 10 (eläkkeellä / viimeisin)

2. Kuinka monta tuntia viikossa arvionne mukaan teette yleensä ansiotyötänne?

_______ tuntia

3. Oletteko joutunut vähentämään työntekoanne selkäoireiden takia?

_______ ei

_______ kyllä, kuinka monta prosenttia arvioisitte työaikanne vähentyneen tilanteesta ennen kuin nykyiset selkäoireenne alkoivat?

________%

_______kyllä, kuinka monta prosenttia arvioisitte työtehonne vähentyneen tilanteesta ennen kuin nykyiset selkäoireenne alkoivat?

________%

4. Kuinka monta tuntia arvionne mukaan täysin terve henkilö tekisi ansiotyötänne viikossa?

_______ tuntia

5. Viime viikon aikana, kuinka monta tuntia arvioitte olleenne poissa töistä johtuen jostain muusta sairaudesta, viasta tai vammasta, kuin selkäoireista?

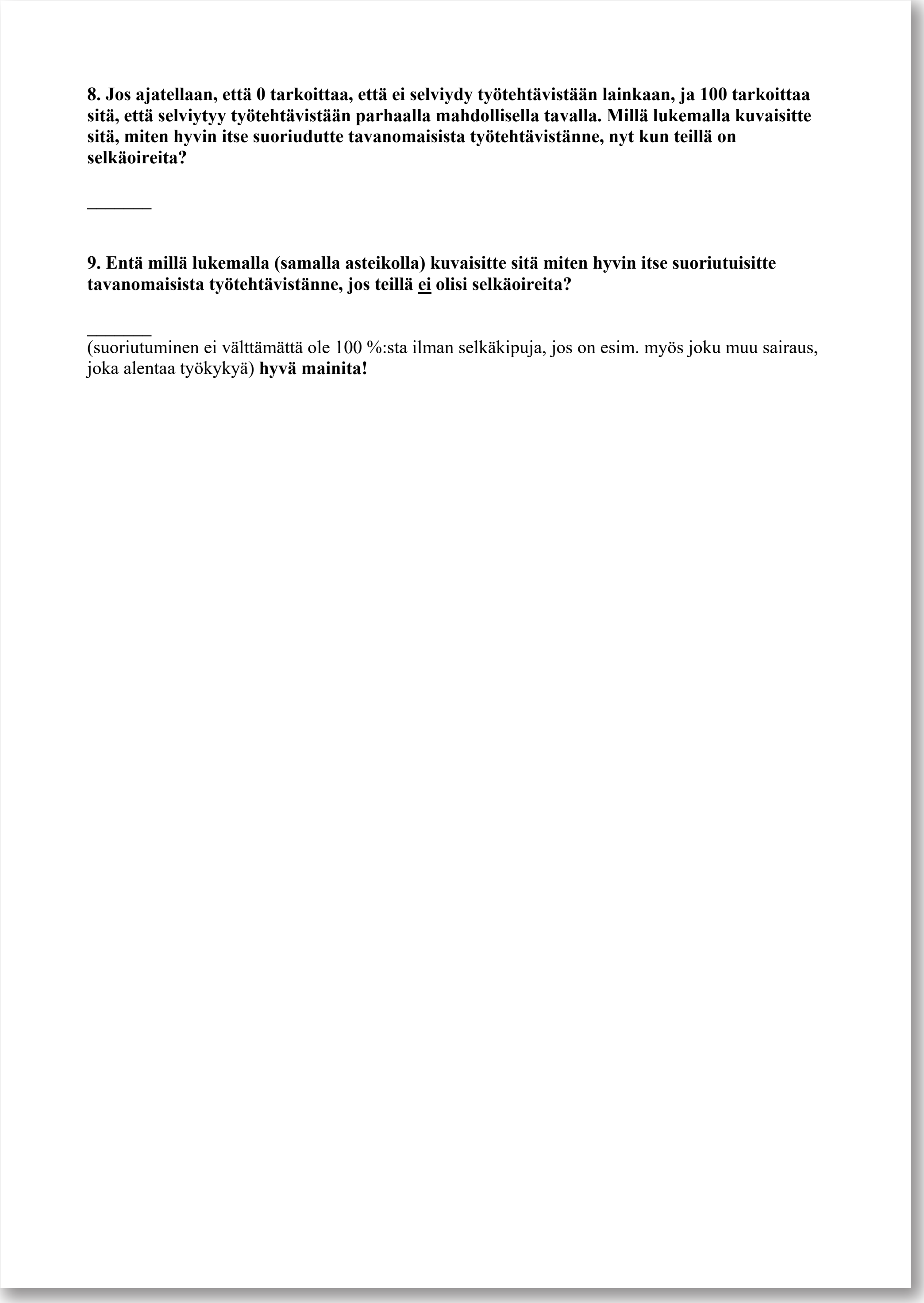
_______ tuntia

6. Viime viikon aikana, kuinka monta tuntia arvioitte olleenne poissa töistä juuri selkäoireiden takia?

_______ tuntia

7. Viime viikon aikana, kuinka monta tuntia arvioitte olleenne poissa töistä loman, vapaa-ajan tai muun vastaavan syyn takia?

_______ tuntia

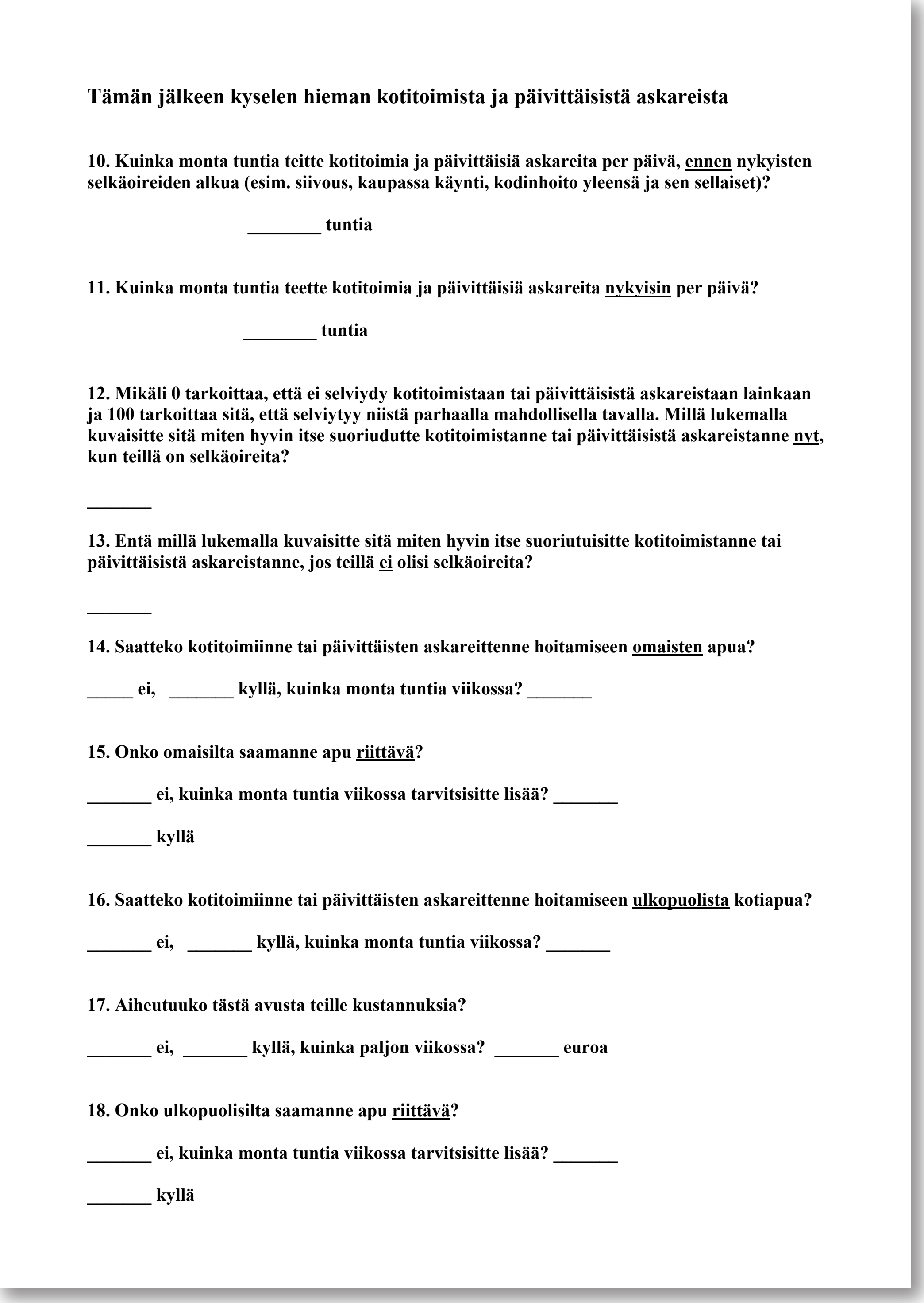


8. Jos ajatellaan, että 0 tarkoittaa, että ei selviydy työtehtävistään lainkaan, ja 100 tarkoittaa sitä, että selviytyy työtehtävistään parhaalla mahdollisella tavalla. Millä lukemalla kuvaisitte sitä, miten hyvin itse suoriudutte tavanomaisista työtehtävistänne, nyt kun teillä on selkäoireita?

____

9. Entä millä lukemalla (samalla asteikolla) kuvaisitte sitä miten hyvin itse suoriutuisitte tavanomaisista työtehtävistänne, jos teillä ei olisi selkäoireita?

____
(suoriutuminen ei välttämättä ole 100 %:sta ilman selkäkipuja, jos on esim. myös joku muu sairaus, joka alentaa työkykyä) **hyvä mainita!**



Tämän jälkeen kyselen hieman kotitoimista ja päivittäisistä askareista

10. Kuinka monta tuntia teitte kotitoimia ja päivittäisiä askareita per päivä, ennen nykyisten selkäoireiden alkua (esim. siivous, kaupassa käynti, kodinhoito yleensä ja sen sellaiset)?

________ tuntia

11. Kuinka monta tuntia teette kotitoimia ja päivittäisiä askareita nykyisin per päivä?

________ tuntia

12. Mikäli 0 tarkoittaa, että ei selviydy kotitoimistaan tai päivittäisistä askareistaan lainkaan ja 100 tarkoittaa sitä, että selviytyy niistä parhaalla mahdollisella tavalla. Millä lukemalla kuvaisitte sitä miten hyvin itse suoriudutte kotitoimistanne tai päivittäisistä askareistanne nyt, kun teillä on selkäoireita?

____

13. Entä millä lukemalla kuvaisitte sitä miten hyvin itse suoriutuisitte kotitoimistanne tai päivittäisistä askareistanne, jos teillä ei olisi selkäoireita?

____

14. Saatteko kotitoimiinne tai päivittäisten askareittenne hoitamiseen omaisten apua?

_____ ei, _______ kyllä, kuinka monta tuntia viikossa? _______

15. Onko omaisilta saamanne apu riittävä?

_______ ei, kuinka monta tuntia viikossa tarvitsisitte lisää? _______

_______ kyllä

16. Saatteko kotitoimiinne tai päivittäisten askareittenne hoitamiseen ulkopuolista kotiapua?

_______ ei, _______ kyllä, kuinka monta tuntia viikossa? _______

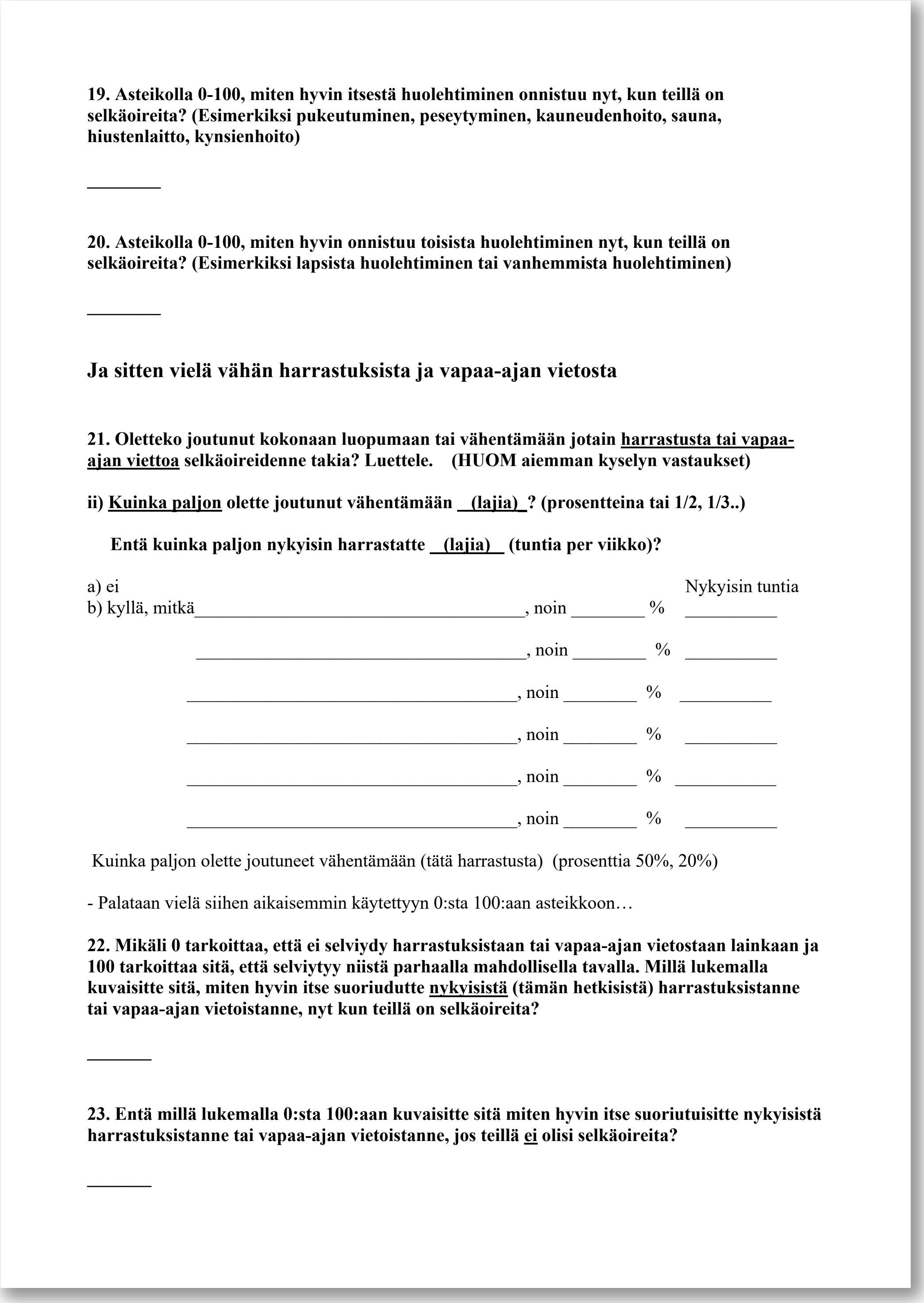
17. Aiheutuuko tästä avusta teille kustannuksia?

_______ ei, _______ kyllä, kuinka paljon viikossa? _______ euroa

18. Onko ulkopuolisilta saamanne apu riittävä?

_______ ei, kuinka monta tuntia viikossa tarvitsisitte lisää? _______

_______ kyllä



19. Asteikolla 0-100, miten hyvin itsestä huolehtiminen onnistuu nyt, kun teillä on selkäoireita? (Esimerkiksi pukeutuminen, peseytyminen, kauneudenhoito, sauna, hiustenlaitto, kynsienhoito)

____

20. Asteikolla 0-100, miten hyvin onnistuu toisista huolehtiminen nyt, kun teillä on selkäoireita? (Esimerkiksi lapsista huolehtiminen tai vanhemmista huolehtiminen)

____

Ja sitten vielä vähän harrastuksista ja vapaa-ajan vietosta

21. Oletteko joutunut kokonaan luopumaan tai vähentämään jotain harrastusta tai vapaa-ajan viettoa selkäoireidenne takia? Luettele. (HUOM aiemman kyselyn vastaukset)

ii) Kuinka paljon olette joutunut vähentämään (lajia) ? (prosentteina tai 1/2, 1/3..)

Entä kuinka paljon nykyisin harrastatte (lajia) (tuntia per viikko)?

a) ei Nykyisin tuntia
b) kyllä, mitkä____________________________________, noin ________ % __________

____________________________________, noin ________ % __________

____________________________________, noin ________ % __________

____________________________________, noin ________ % __________

____________________________________, noin ________ % __________

____________________________________, noin ________ % __________

Kuinka paljon olette joutuneet vähentämään (tätä harrastusta) (prosenttia 50%, 20%)

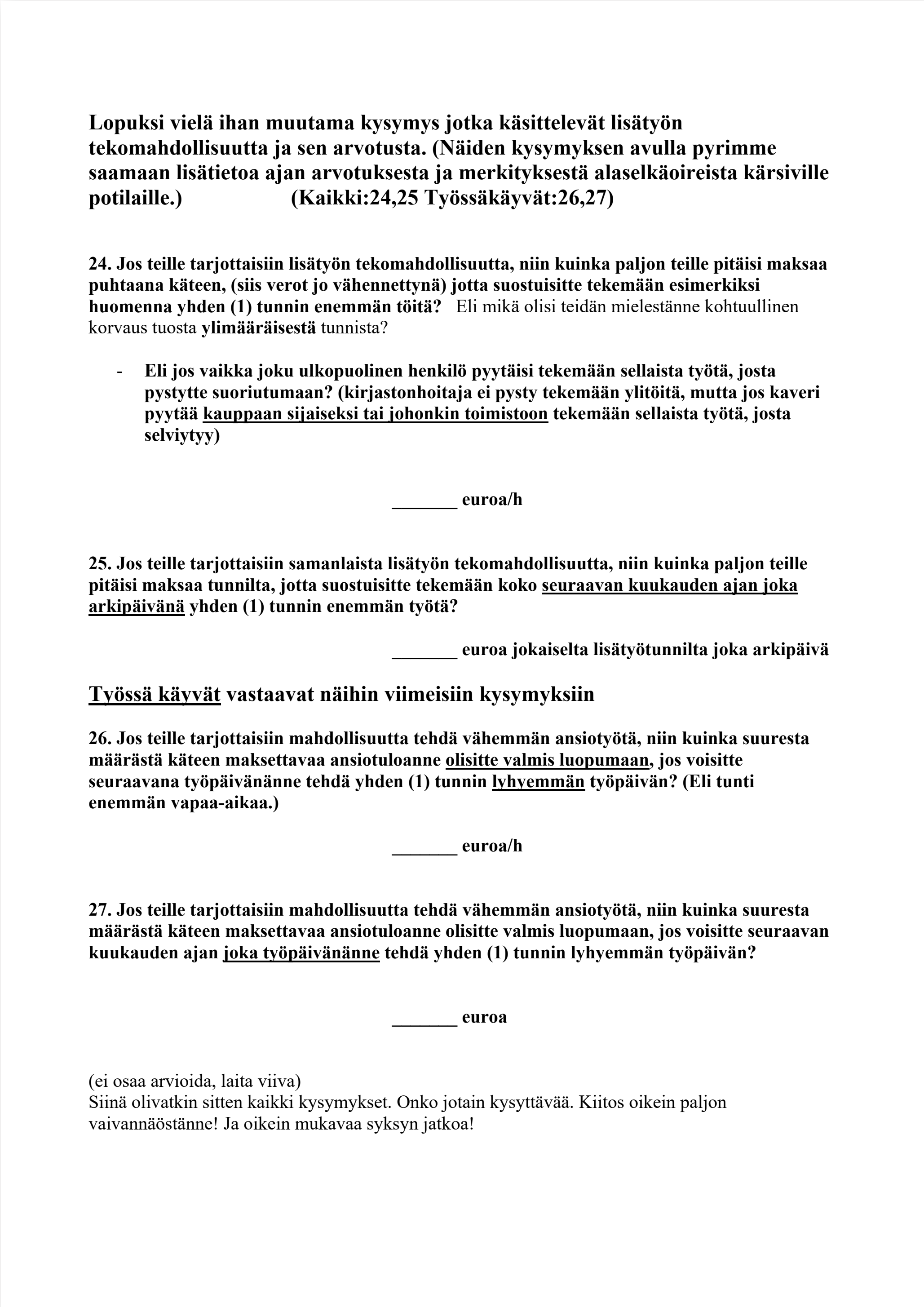
- Palataan vielä siihen aikaisemmin käytettyyn 0:sta 100:aan asteikkoon…

22. Mikäli 0 tarkoittaa, että ei selviydy harrastuksistaan tai vapaa-ajan vietostaan lainkaan ja 100 tarkoittaa sitä, että selviytyy niistä parhaalla mahdollisella tavalla. Millä lukemalla kuvaisitte sitä, miten hyvin itse suoriudutte nykyisistä (tämän hetkisistä) harrastuksistanne tai vapaa-ajan vietoistanne, nyt kun teillä on selkäoireita?

____

23. Entä millä lukemalla 0:sta 100:aan kuvaisitte sitä miten hyvin itse suoriutuisitte nykyisistä harrastuksistanne tai vapaa-ajan vietoistanne, jos teillä ei olisi selkäoireita?

____



Lopuksi vielä ihan muutama kysymys jotka käsittelevät lisätyön tekomahdollisuutta ja sen arvotusta. (Näiden kysymyksen avulla pyrimme saamaan lisätietoa ajan arvotuksesta ja merkityksestä alaselkäoireista kärsiville potilaille.) (Kaikki:24,25 Työssäkäyvät:26,27)

24. Jos teille tarjottaisiin lisätyön tekomahdollisuutta, niin kuinka paljon teille pitäisi maksaa puhtaana käteen, (siis verot jo vähennettynä) jotta suostuisitte tekemään esimerkiksi huomenna yhden (1) tunnin enemmän töitä? Eli mikä olisi teidän mielestänne kohtuullinen korvaus tuosta **ylimääräisestä** tunnista?

- **Eli jos vaikka joku ulkopuolinen henkilö pyytäisi tekemään sellaista työtä, josta pystytte suoriutumaan? (kirjastonhoitaja ei pysty tekemään ylitöitä, mutta jos kaveri pyytää kauppaan sijaiseksi tai johonkin toimistoon tekemään sellaista työtä, josta selviytyy)**

_______ euroa/h

25. Jos teille tarjottaisiin samanlaista lisätyön tekomahdollisuutta, niin kuinka paljon teille pitäisi maksaa tunnilta, jotta suostuisitte tekemään koko seuraavan kuukauden ajan joka arkipäivänä yhden (1) tunnin enemmän työtä?

_______ euroa jokaiselta lisätyötunnilta joka arkipäivä

Työssä käyvät vastaavat näihin viimeisiin kysymyksiin

26. Jos teille tarjottaisiin mahdollisuutta tehdä vähemmän ansiotyötä, niin kuinka suuresta määrästä käteen maksettavaa ansiotuloanne olisitte valmis luopumaan, jos voisitte seuraavana työpäivänänne tehdä yhden (1) tunnin lyhyemmän työpäivän? (Eli tunti enemmän vapaa-aikaa.)

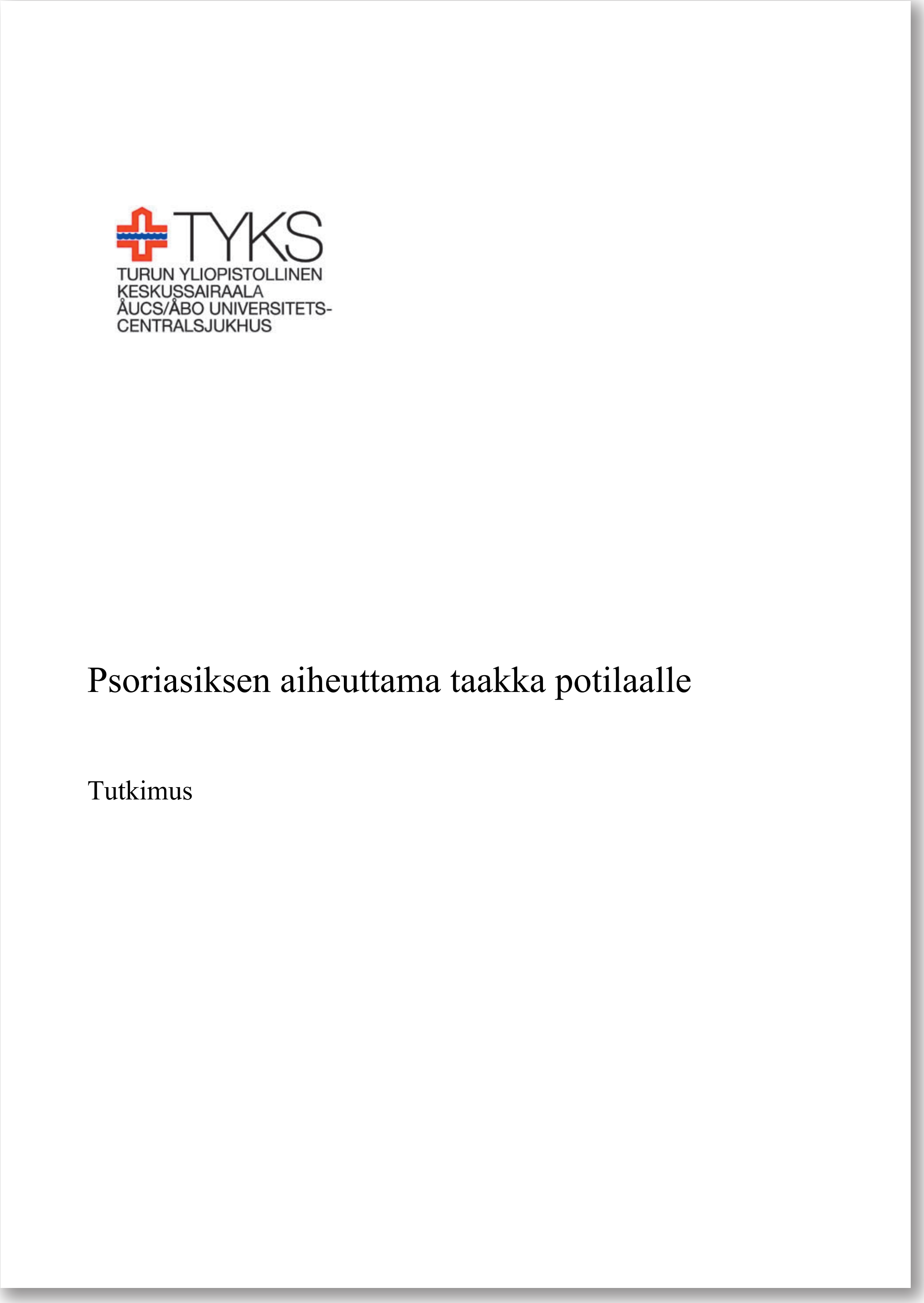
_______ euroa/h

27. Jos teille tarjottaisiin mahdollisuutta tehdä vähemmän ansiotyötä, niin kuinka suuresta määrästä käteen maksettavaa ansiotuloanne olisitte valmis luopumaan, jos voisitte seuraavan kuukauden ajan joka työpäivänänne tehdä yhden (1) tunnin lyhyemmän työpäivän?

_______ euroa

(ei osaa arvioida, laita viiva)
Siinä olivatkin sitten kaikki kysymykset. Onko jotain kysyttävää. Kiitos oikein paljon vaivannäöstänne! Ja oikein mukavaa syksyn jatkoa!

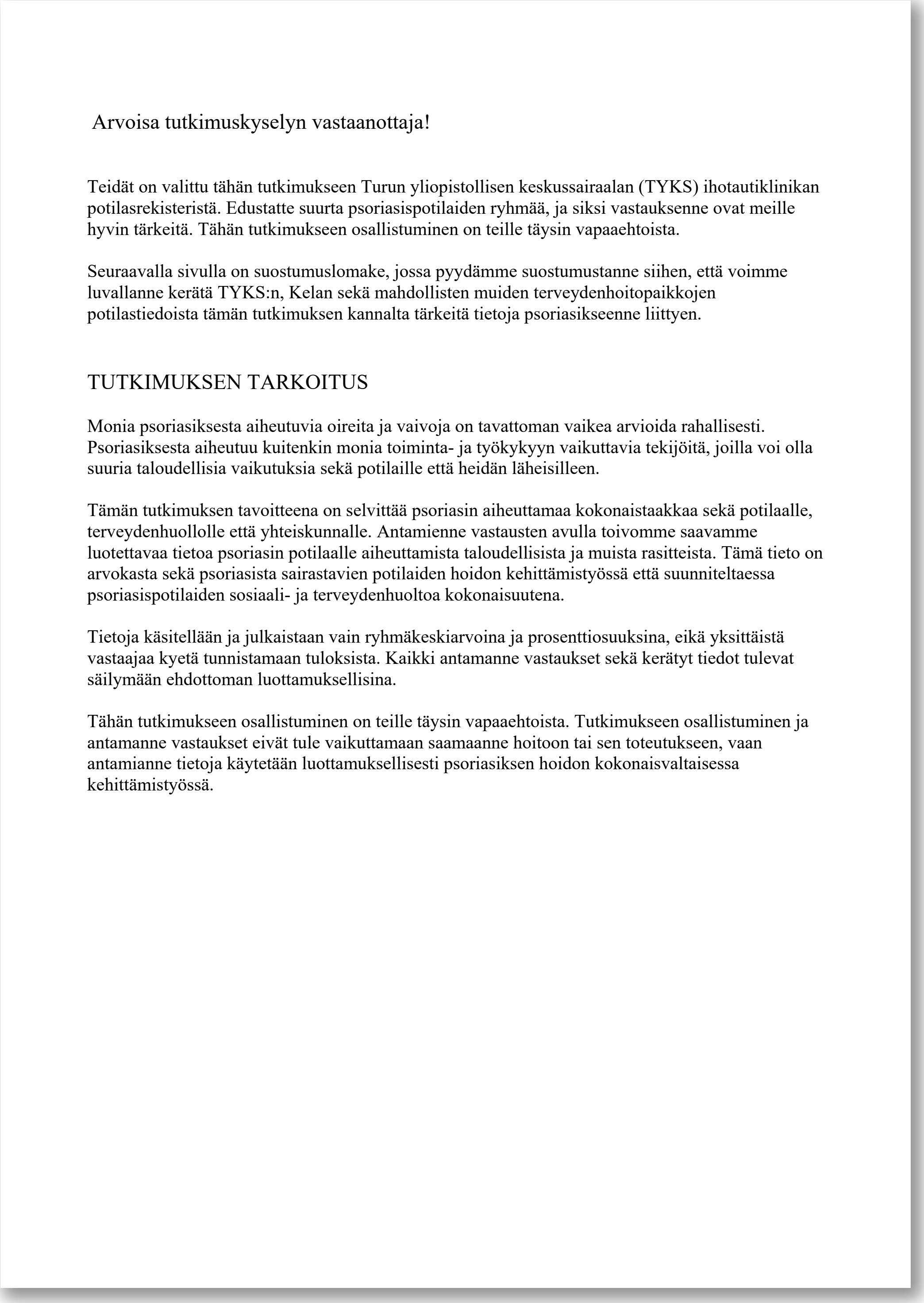
Appendix 2.



TYKS
TURUN YLIOPISTOLLINEN
KESKUSSAIRAALA
ÅUCS/ÅBO UNIVERSITETS-
CENTRALSJUKHUS

Psoriasiksen aiheuttama taakka potilaalle

Tutkimus



Arvoisa tutkimuskyselyn vastaanottaja!

Teidät on valittu tähän tutkimukseen Turun yliopistollisen keskussairaalan (TYKS) ihotautiklinikan potilasrekisteristä. Edustatte suurta psoriasispotilaiden ryhmää, ja siksi vastauksenne ovat meille hyvin tärkeitä. Tähän tutkimukseen osallistuminen on teille täysin vapaaehtoista.

Seuraavalla sivulla on suostumuslomake, jossa pyydämme suostumustanne siihen, että voimme luvallanne kerätä TYKS:n, Kelan sekä mahdollisten muiden terveydenhoitopaikkojen potilastiedoista tämän tutkimuksen kannalta tärkeitä tietoja psoriasikseenne liittyen.

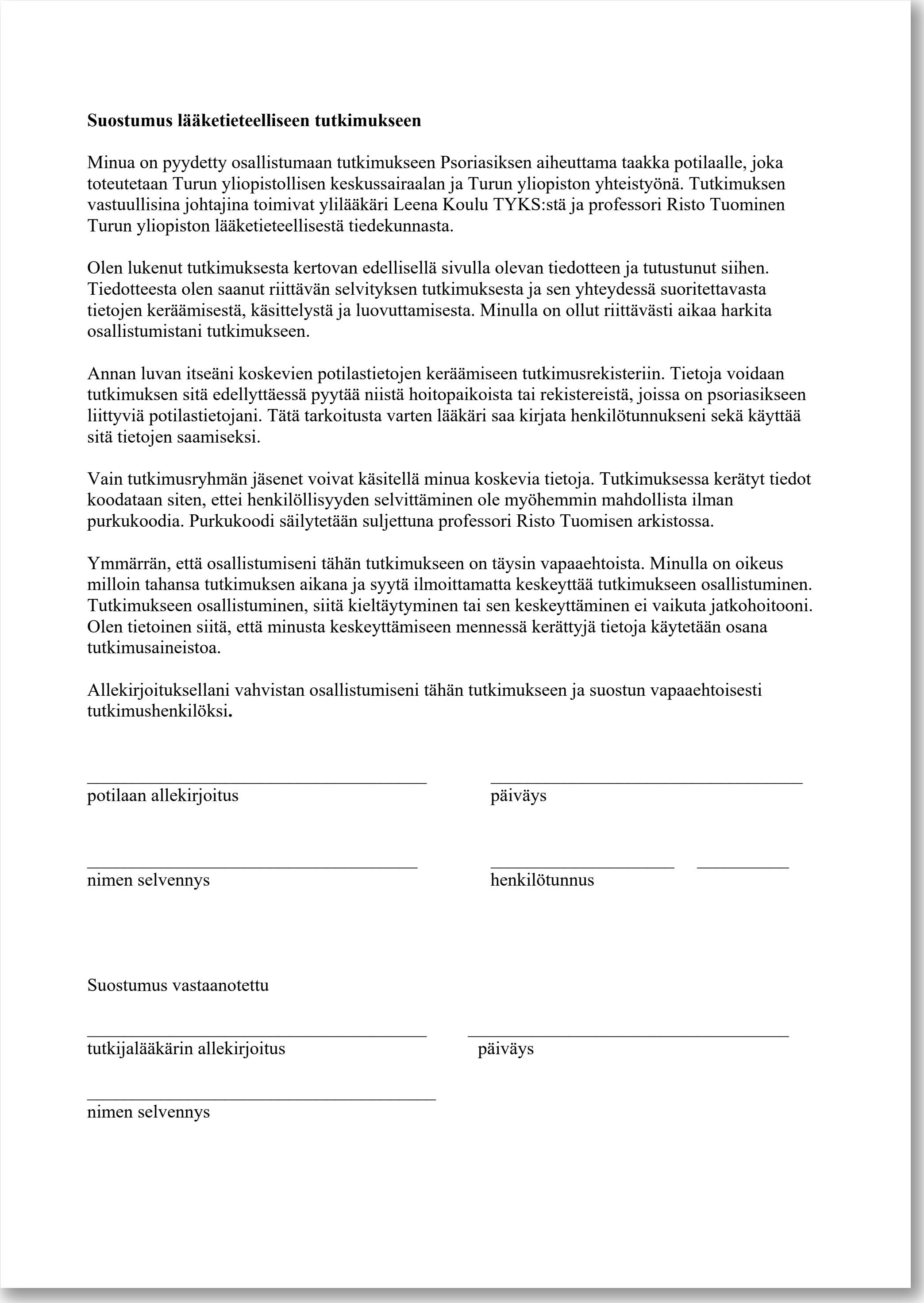
TUTKIMUKSEN TARKOITUS

Monia psoriasiksesta aiheutuvia oireita ja vaivoja on tavattoman vaikea arvioida rahallisesti. Psoriasiksesta aiheutuu kuitenkin monia toiminta- ja työkykyyn vaikuttavia tekijöitä, joilla voi olla suuria taloudellisia vaikutuksia sekä potilaille että heidän läheisilleen.

Tämän tutkimuksen tavoitteena on selvittää psoriasin aiheuttamaa kokonaistaakkaa sekä potilaalle, terveydenhuollolle että yhteiskunnalle. Antamienne vastausten avulla toivomme saavamme luotettavaa tietoa psoriasin potilaalle aiheuttamista taloudellisista ja muista rasitteista. Tämä tieto on arvokasta sekä psoriasista sairastavien potilaiden hoidon kehittämistyössä että suunniteltaessa psoriasispotilaiden sosiaali- ja terveydenhuoltoa kokonaisuutena.

Tietoja käsitellään ja julkaistaan vain ryhmäkeskiarvoina ja prosenttiosuuksina, eikä yksittäistä vastaajaa kyetä tunnistamaan tuloksista. Kaikki antamanne vastaukset sekä kerätyt tiedot tulevat säilymään ehdottoman luottamuksellisina.

Tähän tutkimukseen osallistuminen on teille täysin vapaaehtoista. Tutkimukseen osallistuminen ja antamanne vastaukset eivät tule vaikuttamaan saamaanne hoitoon tai sen toteutukseen, vaan antamianne tietoja käytetään luottamuksellisesti psoriasiksen hoidon kokonaisvaltaisessa kehittämistyössä.



Suostumus lääketieteelliseen tutkimukseen

Minua on pyydetty osallistumaan tutkimukseen Psoriasiksen aiheuttama taakka potilaalle, joka toteutetaan Turun yliopistollisen keskussairaalan ja Turun yliopiston yhteistyönä. Tutkimuksen vastuullisina johtajina toimivat ylilääkäri Leena Koulu TYKS:stä ja professori Risto Tuominen Turun yliopiston lääketieteellisestä tiedekunnasta.

Olen lukenut tutkimuksesta kertovan edellisellä sivulla olevan tiedotteen ja tutustunut siihen. Tiedotteesta olen saanut riittävän selvityksen tutkimuksesta ja sen yhteydessä suoritettavasta tietojen keräämisestä, käsittelystä ja luovuttamisesta. Minulla on ollut riittävästi aikaa harkita osallistumistani tutkimukseen.

Annan luvan itseäni koskevien potilastietojen keräämiseen tutkimusrekisteriin. Tietoja voidaan tutkimuksen sitä edellyttäessä pyytää niistä hoitopaikoista tai rekistereistä, joissa on psoriasikseen liittyviä potilastietojani. Tätä tarkoitusta varten lääkäri saa kirjata henkilötunnukseni sekä käyttää sitä tietojen saamiseksi.

Vain tutkimusryhmän jäsenet voivat käsitellä minua koskevia tietoja. Tutkimuksessa kerätyt tiedot koodataan siten, ettei henkilöllisyyden selvittäminen ole myöhemmin mahdollista ilman purkukoodia. Purkukoodi säilytetään suljettuna professori Risto Tuomisen arkistossa.

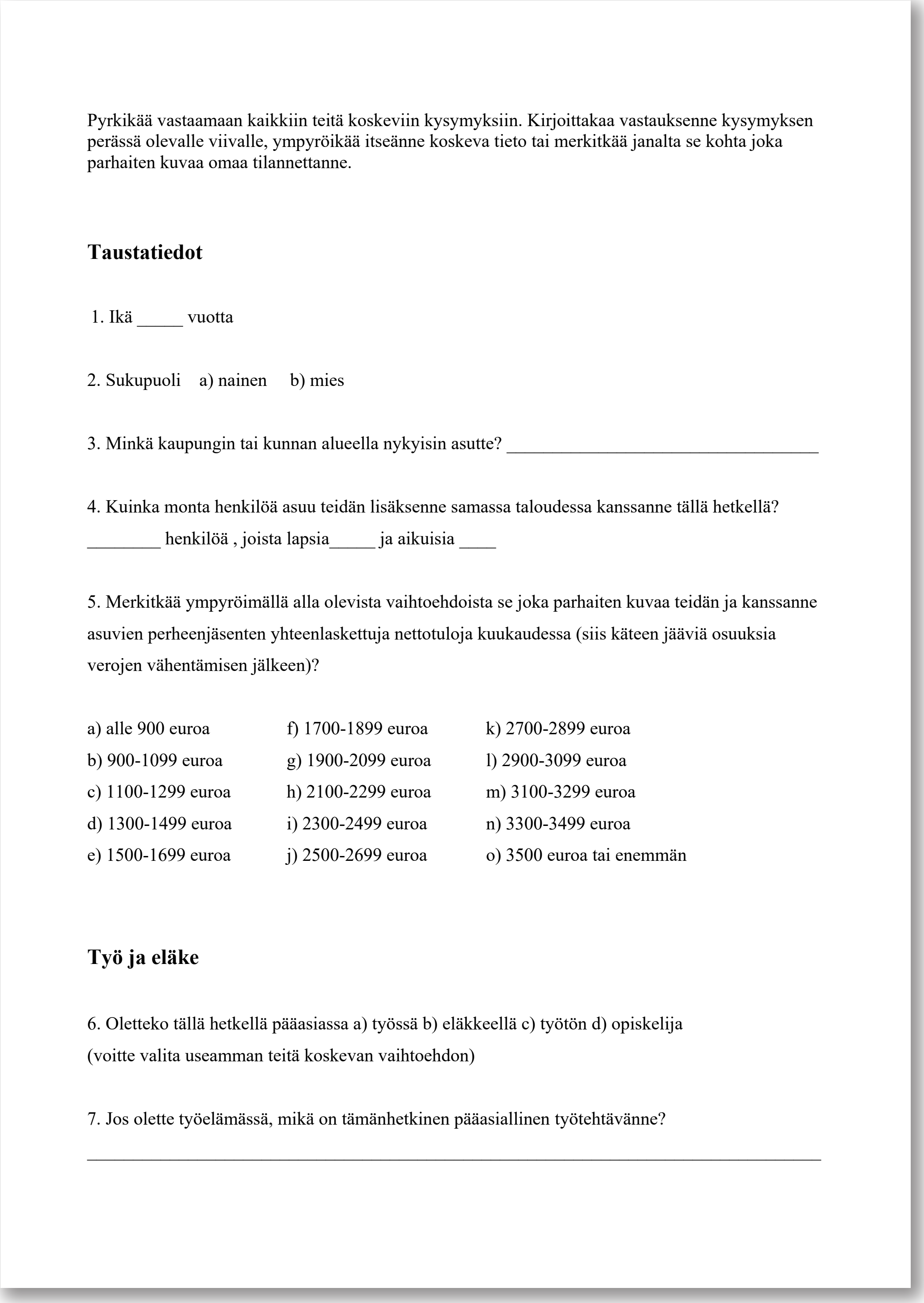
Ymmärrän, että osallistumiseni tähän tutkimukseen on täysin vapaaehtoista. Minulla on oikeus milloin tahansa tutkimuksen aikana ja syytä ilmoittamatta keskeyttää tutkimukseen osallistuminen. Tutkimukseen osallistuminen, siitä kieltäytyminen tai sen keskeyttäminen ei vaikuta jatkohoitooni. Olen tietoinen siitä, että minusta keskeyttämiseen mennessä kerättyjä tietoja käytetään osana tutkimusaineistoa.

Allekirjoituksellani vahvistan osallistumiseni tähän tutkimukseen ja suostun vapaaehtoisesti tutkimushenkilöksi.

potilaan allekirjoitus	päiväys
nimen selvennys	henkilötunnus

Suostumus vastaanotettu

tutkijalääkärin allekirjoitus	päiväys
nimen selvennys	



Pyrkikää vastaamaan kaikkiin teitä koskeviin kysymyksiin. Kirjoittakaa vastauksenne kysymyksen perässä olevalle viivalle, ympyröikää itseänne koskeva tieto tai merkitkää janalta se kohta joka parhaiten kuvaa omaa tilannettanne.

Taustatiedot

1. Ikä _____ vuotta

2. Sukupuoli a) nainen b) mies

3. Minkä kaupungin tai kunnan alueella nykyisin asutte? __________________________________

4. Kuinka monta henkilöä asuu teidän lisäksenne samassa taloudessa kanssanne tällä hetkellä?
________ henkilöä , joista lapsia_____ ja aikuisia ____

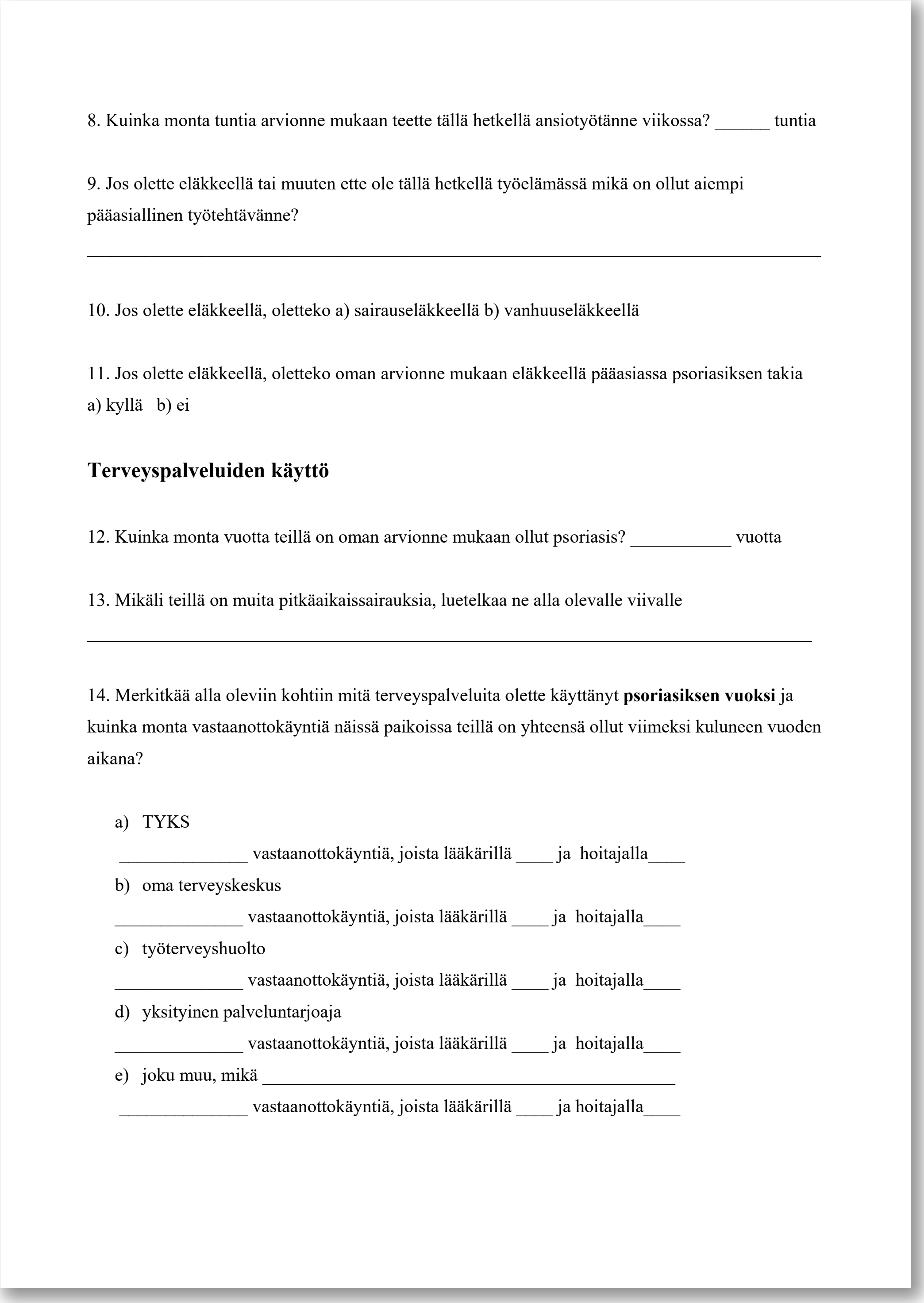
5. Merkitkää ympyröimällä alla olevista vaihtoehdoista se joka parhaiten kuvaa teidän ja kanssanne asuvien perheenjäsenten yhteenlaskettuja nettotuloja kuukaudessa (siis käteen jääviä osuuksia verojen vähentämisen jälkeen)?

a) alle 900 euroa
b) 900-1099 euroa
c) 1100-1299 euroa
d) 1300-1499 euroa
e) 1500-1699 euroa
f) 1700-1899 euroa
g) 1900-2099 euroa
h) 2100-2299 euroa
i) 2300-2499 euroa
j) 2500-2699 euroa
k) 2700-2899 euroa
l) 2900-3099 euroa
m) 3100-3299 euroa
n) 3300-3499 euroa
o) 3500 euroa tai enemmän

Työ ja eläke

6. Oletteko tällä hetkellä pääasiassa a) työssä b) eläkkeellä c) työtön d) opiskelija
(voitte valita useamman teitä koskevan vaihtoehdon)

7. Jos olette työelämässä, mikä on tämänhetkinen pääasiallinen työtehtävänne?
____



8. Kuinka monta tuntia arvionne mukaan teette tällä hetkellä ansiotyötänne viikossa? ______ tuntia

9. Jos olette eläkkeellä tai muuten ette ole tällä hetkellä työelämässä mikä on ollut aiempi pääasiallinen työtehtävänne?

____

10. Jos olette eläkkeellä, oletteko a) sairauseläkkeellä b) vanhuuseläkkeellä

11. Jos olette eläkkeellä, oletteko oman arvionne mukaan eläkkeellä pääasiassa psoriasiksen takia
a) kyllä b) ei

Terveyspalveluiden käyttö

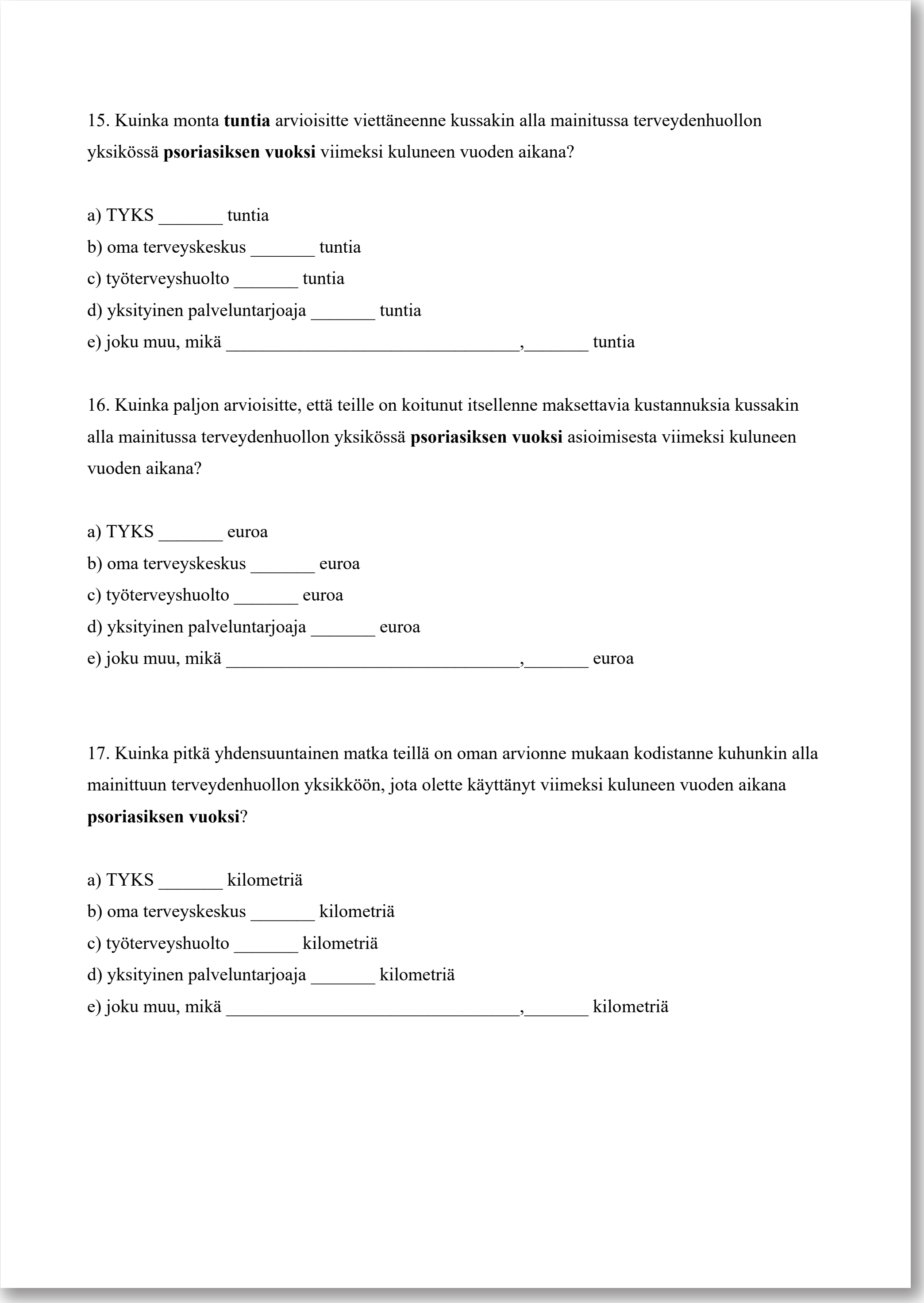
12. Kuinka monta vuotta teillä on oman arvionne mukaan ollut psoriasis? ___________ vuotta

13. Mikäli teillä on muita pitkäaikaissairauksia, luetelkaa ne alla olevalle viivalle

____

14. Merkitkää alla oleviin kohtiin mitä terveyspalveluita olette käyttänyt **psoriasiksen vuoksi** ja kuinka monta vastaanottokäyntiä näissä paikoissa teillä on yhteensä ollut viimeksi kuluneen vuoden aikana?

a) TYKS
______________ vastaanottokäyntiä, joista lääkärillä ____ ja hoitajalla____
b) oma terveyskeskus
______________ vastaanottokäyntiä, joista lääkärillä ____ ja hoitajalla____
c) työterveyshuolto
______________ vastaanottokäyntiä, joista lääkärillä ____ ja hoitajalla____
d) yksityinen palveluntarjoaja
______________ vastaanottokäyntiä, joista lääkärillä ____ ja hoitajalla____
e) joku muu, mikä ____
______________ vastaanottokäyntiä, joista lääkärillä ____ ja hoitajalla____



15. Kuinka monta **tuntia** arvioisitte viettäneenne kussakin alla mainitussa terveydenhuollon yksikössä **psoriasiksen vuoksi** viimeksi kuluneen vuoden aikana?

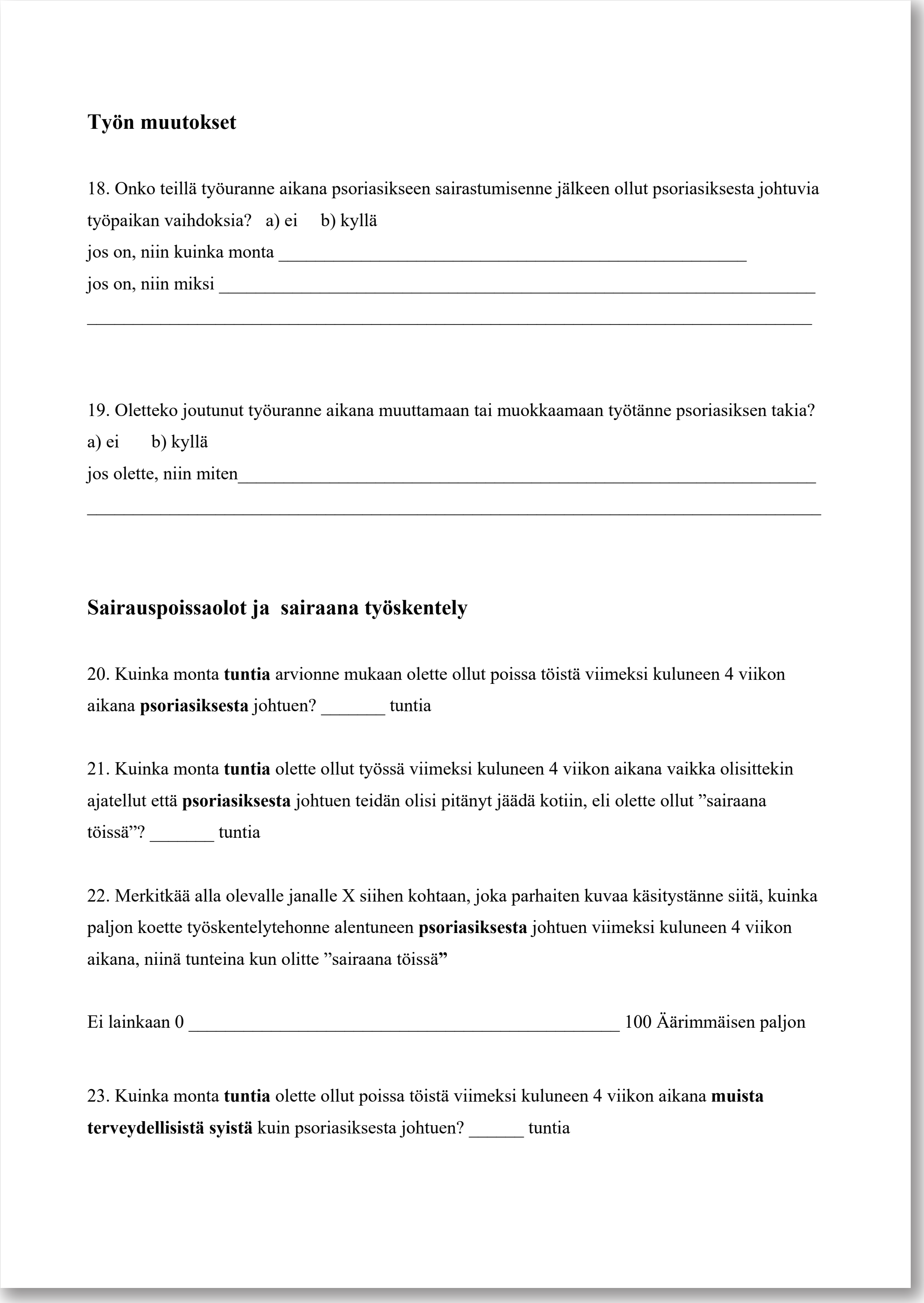
a) TYKS _______ tuntia
b) oma terveyskeskus _______ tuntia
c) työterveyshuolto _______ tuntia
d) yksityinen palveluntarjoaja _______ tuntia
e) joku muu, mikä ________________________________,_______ tuntia

16. Kuinka paljon arvioisitte, että teille on koitunut itsellenne maksettavia kustannuksia kussakin alla mainitussa terveydenhuollon yksikössä **psoriasiksen vuoksi** asioimisesta viimeksi kuluneen vuoden aikana?

a) TYKS _______ euroa
b) oma terveyskeskus _______ euroa
c) työterveyshuolto _______ euroa
d) yksityinen palveluntarjoaja _______ euroa
e) joku muu, mikä ________________________________,_______ euroa

17. Kuinka pitkä yhdensuuntainen matka teillä on oman arvionne mukaan kodistanne kuhunkin alla mainittuun terveydenhuollon yksikköön, jota olette käyttänyt viimeksi kuluneen vuoden aikana **psoriasiksen vuoksi**?

a) TYKS _______ kilometriä
b) oma terveyskeskus _______ kilometriä
c) työterveyshuolto _______ kilometriä
d) yksityinen palveluntarjoaja _______ kilometriä
e) joku muu, mikä ________________________________,_______ kilometriä



Työn muutokset

18. Onko teillä työuranne aikana psoriasikseen sairastumisenne jälkeen ollut psoriasiksesta johtuvia työpaikan vaihdoksia? a) ei b) kyllä

jos on, niin kuinka monta ____

jos on, niin miksi ____

____

19. Oletteko joutunut työuranne aikana muuttamaan tai muokkaamaan työtänne psoriasiksen takia?

a) ei b) kyllä

jos olette, niin miten____

____

Sairauspoissaolot ja sairaana työskentely

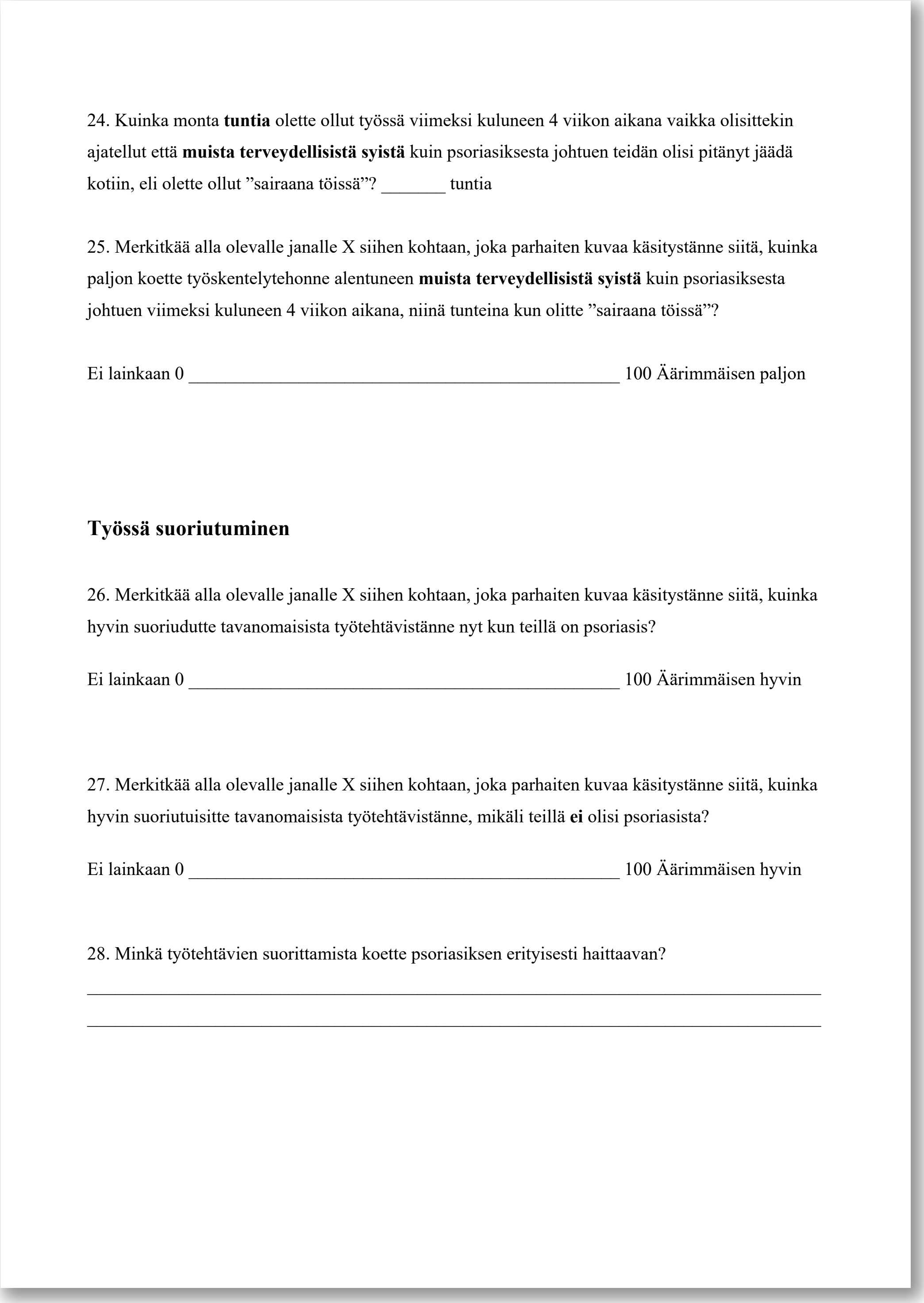
20. Kuinka monta **tuntia** arvionne mukaan olette ollut poissa töistä viimeksi kuluneen 4 viikon aikana **psoriasiksesta** johtuen? _______ tuntia

21. Kuinka monta **tuntia** olette ollut työssä viimeksi kuluneen 4 viikon aikana vaikka olisittekin ajatellut että **psoriasiksesta** johtuen teidän olisi pitänyt jäädä kotiin, eli olette ollut ”sairaana töissä”? _______ tuntia

22. Merkitkää alla olevalle janalle X siihen kohtaan, joka parhaiten kuvaa käsitystänne siitä, kuinka paljon koette työskentelytehonne alentuneen **psoriasiksesta** johtuen viimeksi kuluneen 4 viikon aikana, niinä tunteina kun olitte ”sairaana töissä**”**

Ei lainkaan 0 ____ 100 Äärimmäisen paljon

23. Kuinka monta **tuntia** olette ollut poissa töistä viimeksi kuluneen 4 viikon aikana **muista terveydellisistä syistä** kuin psoriasiksesta johtuen? ______ tuntia



24. Kuinka monta **tuntia** olette ollut työssä viimeksi kuluneen 4 viikon aikana vaikka olisittekin ajatellut että **muista terveydellisistä syistä** kuin psoriasiksesta johtuen teidän olisi pitänyt jäädä kotiin, eli olette ollut ”sairaana töissä”? _______ tuntia

25. Merkitkää alla olevalle janalle X siihen kohtaan, joka parhaiten kuvaa käsitystänne siitä, kuinka paljon koette työskentelytehonne alentuneen **muista terveydellisistä syistä** kuin psoriasiksesta johtuen viimeksi kuluneen 4 viikon aikana, niinä tunteina kun olitte ”sairaana töissä”?

Ei lainkaan 0 ____ 100 Äärimmäisen paljon

Työssä suoriutuminen

26. Merkitkää alla olevalle janalle X siihen kohtaan, joka parhaiten kuvaa käsitystänne siitä, kuinka hyvin suoriudutte tavanomaisista työtehtävistänne nyt kun teillä on psoriasis?

Ei lainkaan 0 ____ 100 Äärimmäisen hyvin

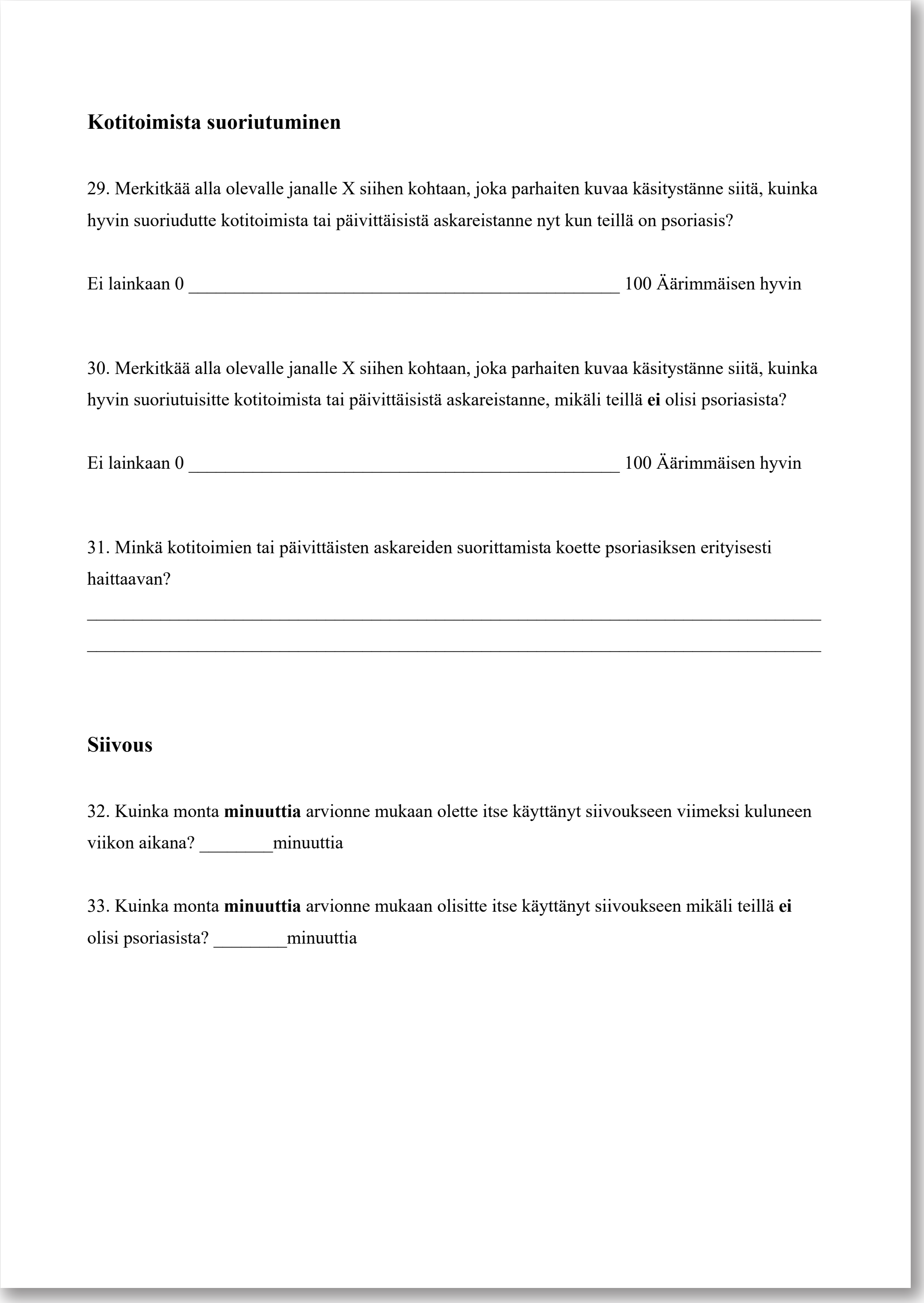
27. Merkitkää alla olevalle janalle X siihen kohtaan, joka parhaiten kuvaa käsitystänne siitä, kuinka hyvin suoriutuisitte tavanomaisista työtehtävistänne, mikäli teillä **ei** olisi psoriasista?

Ei lainkaan 0 ____ 100 Äärimmäisen hyvin

28. Minkä työtehtävien suorittamista koette psoriasiksen erityisesti haittaavan?

____

____



Kotitoimista suoriutuminen

29. Merkitkää alla olevalle janalle X siihen kohtaan, joka parhaiten kuvaa käsitystänne siitä, kuinka hyvin suoriudutte kotitoimista tai päivittäisistä askareistanne nyt kun teillä on psoriasis?

Ei lainkaan 0 ____ 100 Äärimmäisen hyvin

30. Merkitkää alla olevalle janalle X siihen kohtaan, joka parhaiten kuvaa käsitystänne siitä, kuinka hyvin suoriutuisitte kotitoimista tai päivittäisistä askareistanne, mikäli teillä **ei** olisi psoriasista?

Ei lainkaan 0 ____ 100 Äärimmäisen hyvin

31. Minkä kotitoimien tai päivittäisten askareiden suorittamista koette psoriasiksen erityisesti haittaavan?

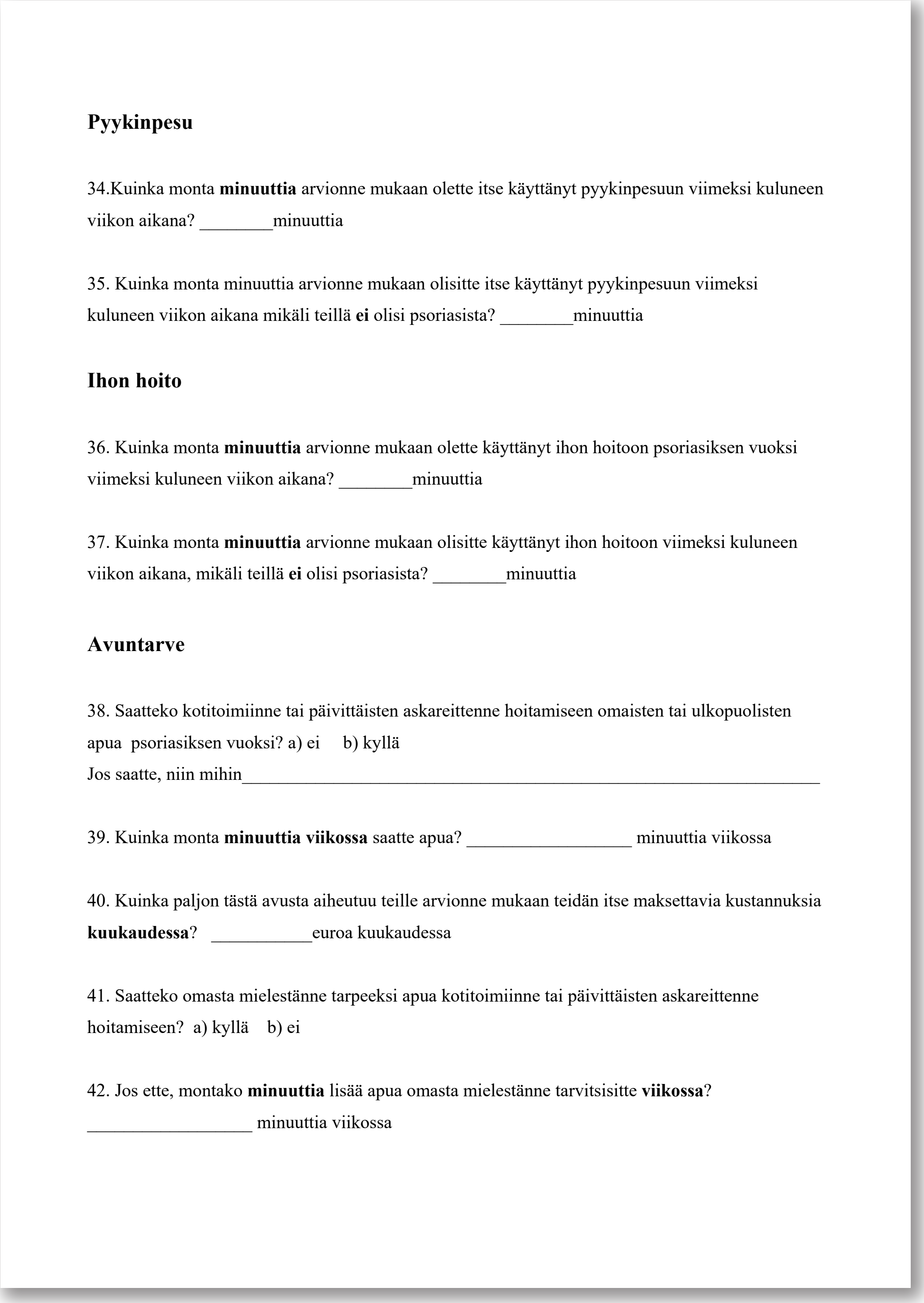
____

____

Siivous

32. Kuinka monta **minuuttia** arvionne mukaan olette itse käyttänyt siivoukseen viimeksi kuluneen viikon aikana? ________minuuttia

33. Kuinka monta **minuuttia** arvionne mukaan olisitte itse käyttänyt siivoukseen mikäli teillä **ei** olisi psoriasista? ________minuuttia



Pyykinpesu

34.Kuinka monta **minuuttia** arvionne mukaan olette itse käyttänyt pyykinpesuun viimeksi kuluneen viikon aikana? ________minuuttia

35. Kuinka monta minuuttia arvionne mukaan olisitte itse käyttänyt pyykinpesuun viimeksi kuluneen viikon aikana mikäli teillä **ei** olisi psoriasista? ________minuuttia

Ihon hoito

36. Kuinka monta **minuuttia** arvionne mukaan olette käyttänyt ihon hoitoon psoriasiksen vuoksi viimeksi kuluneen viikon aikana? ________minuuttia

37. Kuinka monta **minuuttia** arvionne mukaan olisitte käyttänyt ihon hoitoon viimeksi kuluneen viikon aikana, mikäli teillä **ei** olisi psoriasista? ________minuuttia

Avuntarve

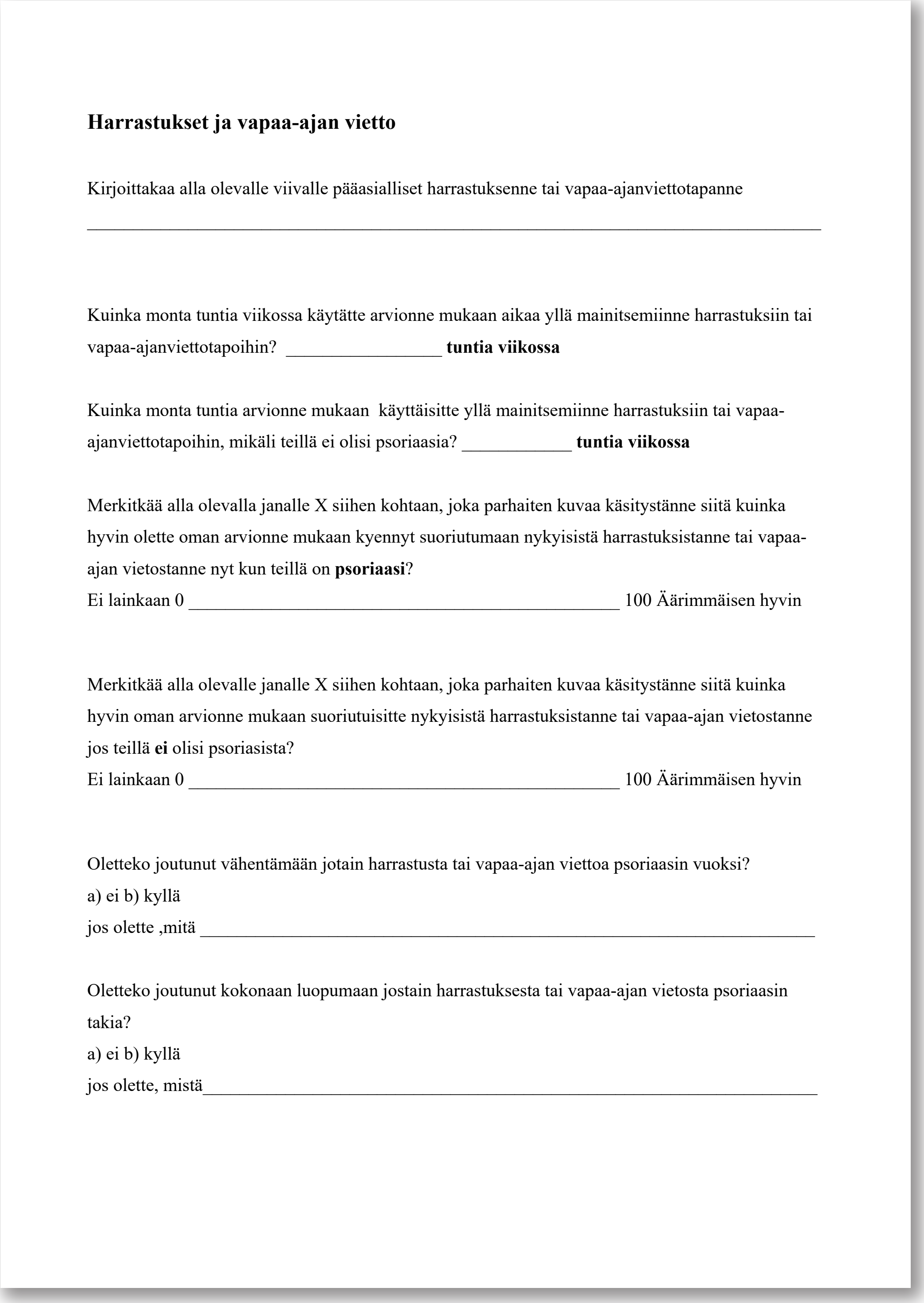
38. Saatteko kotitoimiinne tai päivittäisten askareittenne hoitamiseen omaisten tai ulkopuolisten apua psoriasiksen vuoksi? a) ei b) kyllä
Jos saatte, niin mihin____

39. Kuinka monta **minuuttia viikossa** saatte apua? __________________ minuuttia viikossa

40. Kuinka paljon tästä avusta aiheutuu teille arvionne mukaan teidän itse maksettavia kustannuksia **kuukaudessa**? ___________euroa kuukaudessa

41. Saatteko omasta mielestänne tarpeeksi apua kotitoimiinne tai päivittäisten askareittenne hoitamiseen? a) kyllä b) ei

42. Jos ette, montako **minuuttia** lisää apua omasta mielestänne tarvitsisitte **viikossa**?
__________________ minuuttia viikossa



Harrastukset ja vapaa-ajan vietto

Kirjoittakaa alla olevalle viivalle pääasialliset harrastuksenne tai vapaa-ajanviettotapanne

____

Kuinka monta tuntia viikossa käytätte arvionne mukaan aikaa yllä mainitsemiinne harrastuksiin tai vapaa-ajanviettotapoihin? ________________ **tuntia viikossa**

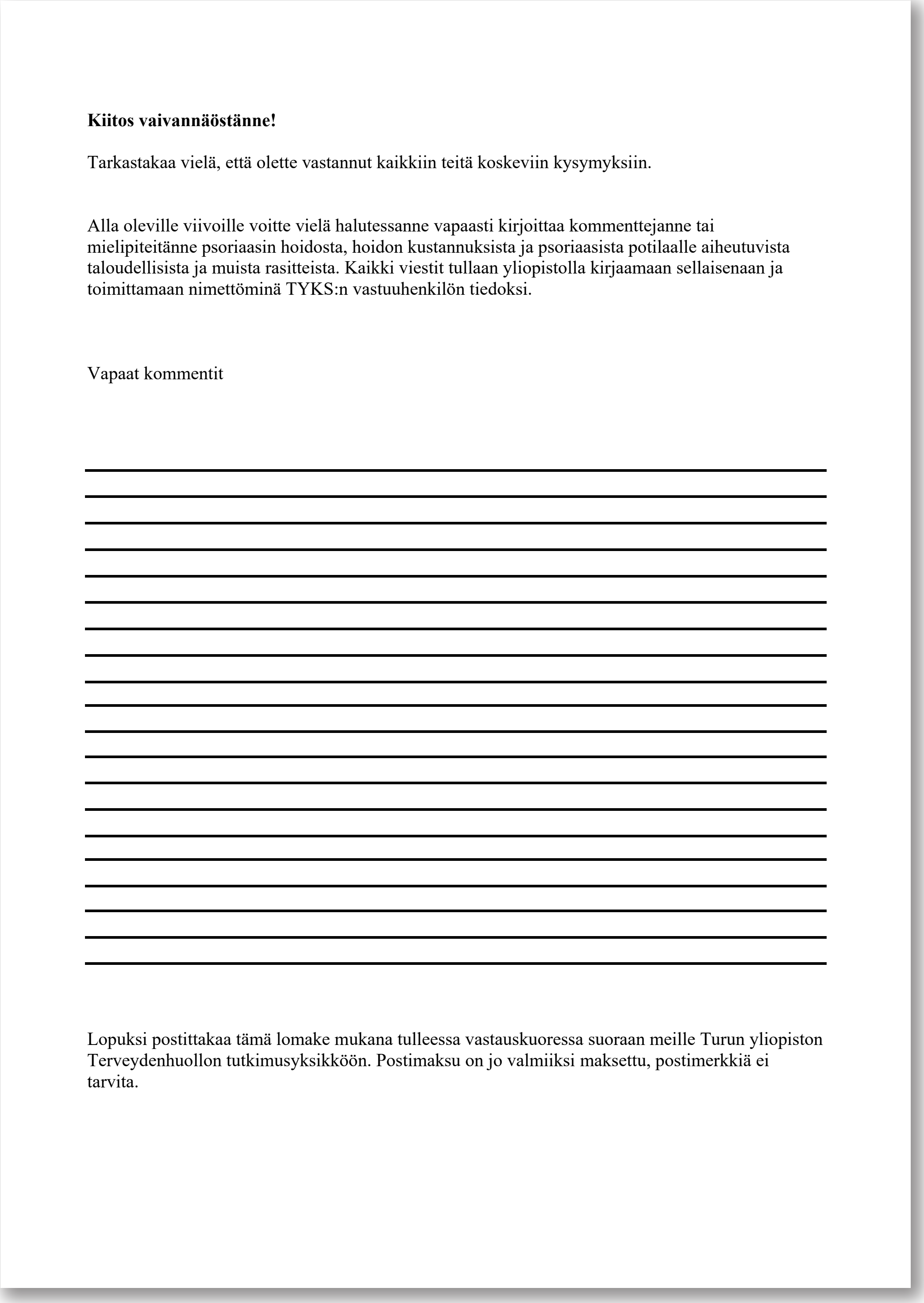
Kuinka monta tuntia arvionne mukaan käyttäisitte yllä mainitsemiinne harrastuksiin tai vapaa-ajanviettotapoihin, mikäli teillä ei olisi psoriaasia? ___________ **tuntia viikossa**

Merkitkää alla olevalla janalle X siihen kohtaan, joka parhaiten kuvaa käsitystänne siitä kuinka hyvin olette oman arvionne mukaan kyennyt suoriutumaan nykyisistä harrastuksistanne tai vapaa-ajan vietostanne nyt kun teillä on **psoriaasi**?
Ei lainkaan 0 ____ 100 Äärimmäisen hyvin

Merkitkää alla olevalle janalle X siihen kohtaan, joka parhaiten kuvaa käsitystänne siitä kuinka hyvin oman arvionne mukaan suoriutuisitte nykyisistä harrastuksistanne tai vapaa-ajan vietostanne jos teillä **ei** olisi psoriasista?
Ei lainkaan 0 ____ 100 Äärimmäisen hyvin

Oletteko joutunut vähentämään jotain harrastusta tai vapaa-ajan viettoa psoriaasin vuoksi?
a) ei b) kyllä
jos olette ,mitä ____

Oletteko joutunut kokonaan luopumaan jostain harrastuksesta tai vapaa-ajan vietosta psoriaasin takia?
a) ei b) kyllä
jos olette, mistä____



Kiitos vaivannäöstänne!

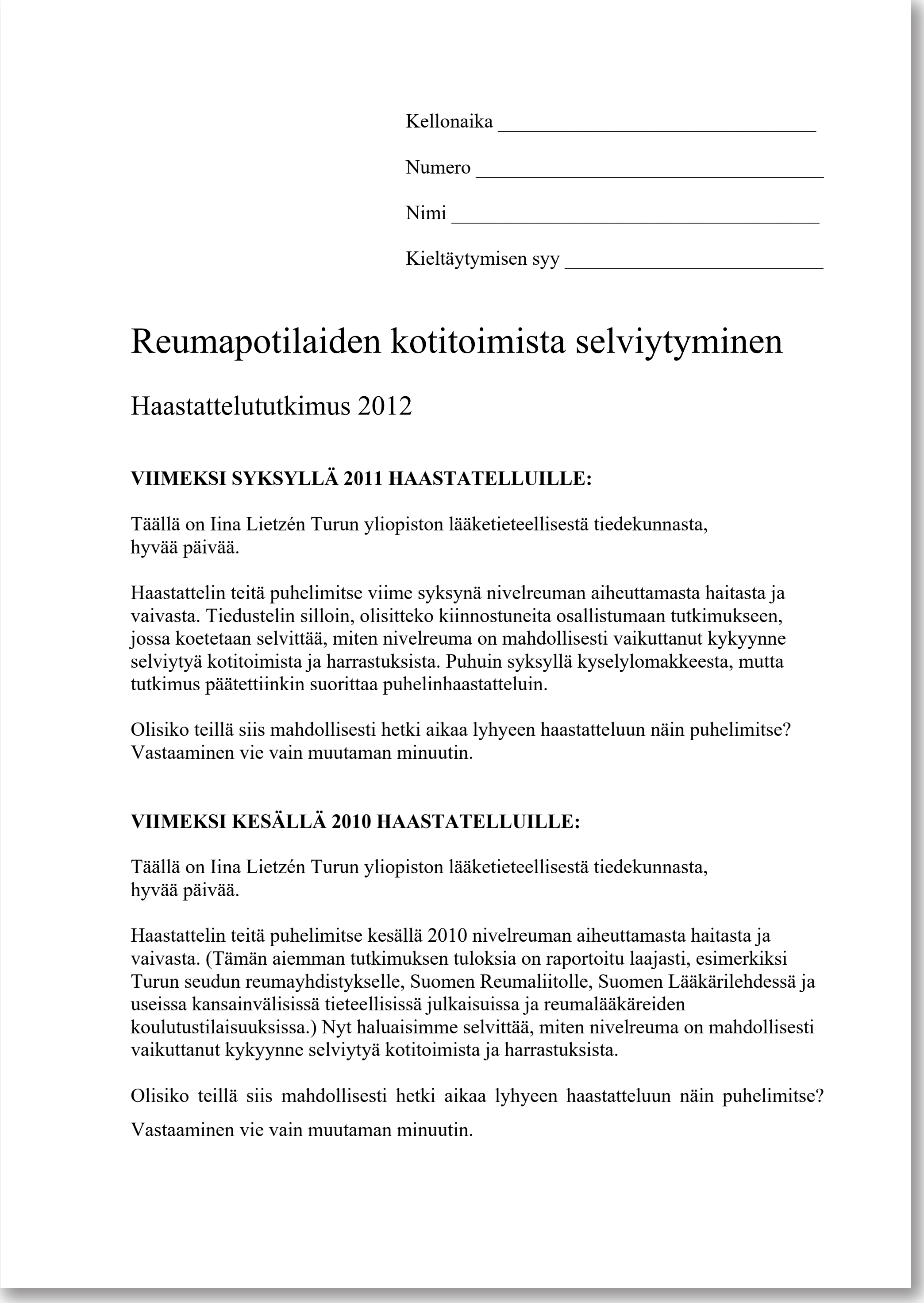
Tarkastakaa vielä, että olette vastannut kaikkiin teitä koskeviin kysymyksiin.

Alla oleville viivoille voitte vielä halutessanne vapaasti kirjoittaa kommenttejanne tai mielipiteitänne psoriaasin hoidosta, hoidon kustannuksista ja psoriaasista potilaalle aiheutuvista taloudellisista ja muista rasitteista. Kaikki viestit tullaan yliopistolla kirjaamaan sellaisenaan ja toimittamaan nimettöminä TYKS:n vastuuhenkilön tiedoksi.

Vapaat kommentit

Lopuksi postittakaa tämä lomake mukana tulleessa vastauskuoressa suoraan meille Turun yliopiston Terveydenhuollon tutkimusyksikköön. Postimaksu on jo valmiiksi maksettu, postimerkkiä ei tarvita.

Appendix 3.



Kellonaika ______________________________

Numero _________________________________

Nimi ___________________________________

Kieltäytymisen syy _________________________

Reumapotilaiden kotitoimista selviytyminen

Haastattelututkimus 2012

VIIMEKSI SYKSYLLÄ 2011 HAASTATELLUILLE:

Täällä on Iina Lietzén Turun yliopiston lääketieteellisestä tiedekunnasta,
hyvää päivää.

Haastattelin teitä puhelimitse viime syksynä nivelreuman aiheuttamasta haitasta ja vaivasta. Tiedustelin silloin, olisitteko kiinnostuneita osallistumaan tutkimukseen, jossa koetetaan selvittää, miten nivelreuma on mahdollisesti vaikuttanut kykyynne selviytyä kotitoimista ja harrastuksista. Puhuin syksyllä kyselylomakkeesta, mutta tutkimus päätettiinkin suorittaa puhelinhaastatteluin.

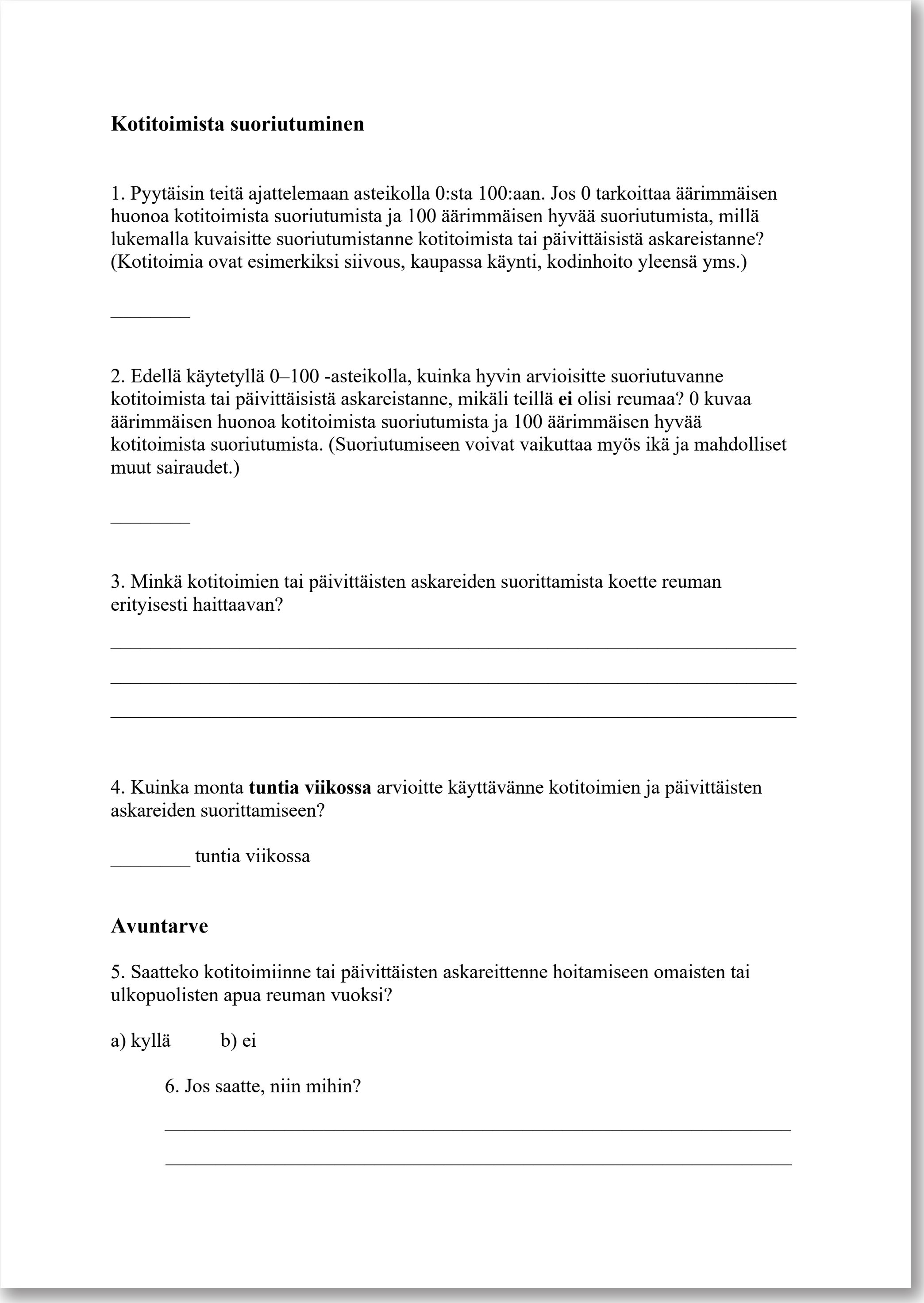
Olisiko teillä siis mahdollisesti hetki aikaa lyhyeen haastatteluun näin puhelimitse? Vastaaminen vie vain muutaman minuutin.

VIIMEKSI KESÄLLÄ 2010 HAASTATELLUILLE:

Täällä on Iina Lietzén Turun yliopiston lääketieteellisestä tiedekunnasta,
hyvää päivää.

Haastattelin teitä puhelimitse kesällä 2010 nivelreuman aiheuttamasta haitasta ja vaivasta. (Tämän aiemman tutkimuksen tuloksia on raportoitu laajasti, esimerkiksi Turun seudun reumayhdistykselle, Suomen Reumaliitolle, Suomen Lääkärilehdessä ja useissa kansainvälisissä tieteellisissä julkaisuissa ja reumalääkäreiden koulutustilaisuuksissa.) Nyt haluaisimme selvittää, miten nivelreuma on mahdollisesti vaikuttanut kykyynne selviytyä kotitoimista ja harrastuksista.

Olisiko teillä siis mahdollisesti hetki aikaa lyhyeen haastatteluun näin puhelimitse? Vastaaminen vie vain muutaman minuutin.



Kotitoimista suoriutuminen

1. Pyytäisin teitä ajattelemaan asteikolla 0:sta 100:aan. Jos 0 tarkoittaa äärimmäisen huonoa kotitoimista suoriutumista ja 100 äärimmäisen hyvää suoriutumista, millä lukemalla kuvaisitte suoriutumistanne kotitoimista tai päivittäisistä askareistanne? (Kotitoimia ovat esimerkiksi siivous, kaupassa käynti, kodinhoito yleensä yms.)

____

2. Edellä käytetyllä 0–100 -asteikolla, kuinka hyvin arvioisitte suoriutuvanne kotitoimista tai päivittäisistä askareistanne, mikäli teillä **ei** olisi reumaa? 0 kuvaa äärimmäisen huonoa kotitoimista suoriutumista ja 100 äärimmäisen hyvää kotitoimista suoriutumista. (Suoriutumiseen voivat vaikuttaa myös ikä ja mahdolliset muut sairaudet.)

____

3. Minkä kotitoimien tai päivittäisten askareiden suorittamista koette reuman erityisesti haittaavan?

____

____

____

4. Kuinka monta **tuntia viikossa** arvioitte käyttävänne kotitoimien ja päivittäisten askareiden suorittamiseen?

________ tuntia viikossa

Avuntarve

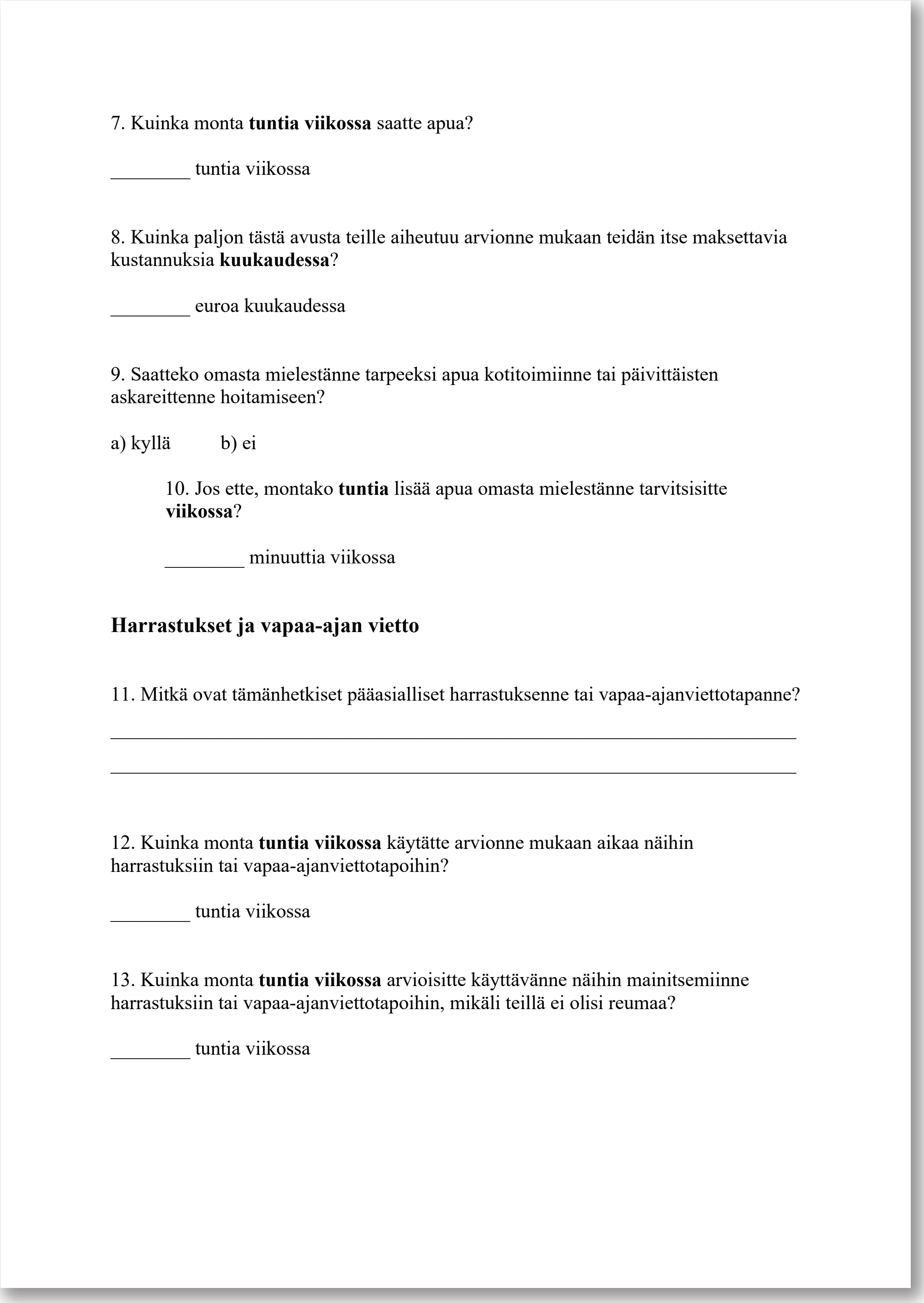
5. Saatteko kotitoimiinne tai päivittäisten askareittenne hoitamiseen omaisten tai ulkopuolisten apua reuman vuoksi?

a) kyllä b) ei

6. Jos saatte, niin mihin?

____

____



7. Kuinka monta **tuntia viikossa** saatte apua?

________ tuntia viikossa

8. Kuinka paljon tästä avusta teille aiheutuu arvionne mukaan teidän itse maksettavia kustannuksia **kuukaudessa**?

________ euroa kuukaudessa

9. Saatteko omasta mielestänne tarpeeksi apua kotitoimiinne tai päivittäisten askareittenne hoitamiseen?

a) kyllä b) ei

10. Jos ette, montako **tuntia** lisää apua omasta mielestänne tarvitsisitte **viikossa**?

________ minuuttia viikossa

Harrastukset ja vapaa-ajan vietto

11. Mitkä ovat tämänhetkiset pääasialliset harrastuksenne tai vapaa-ajanviettotapanne?

____

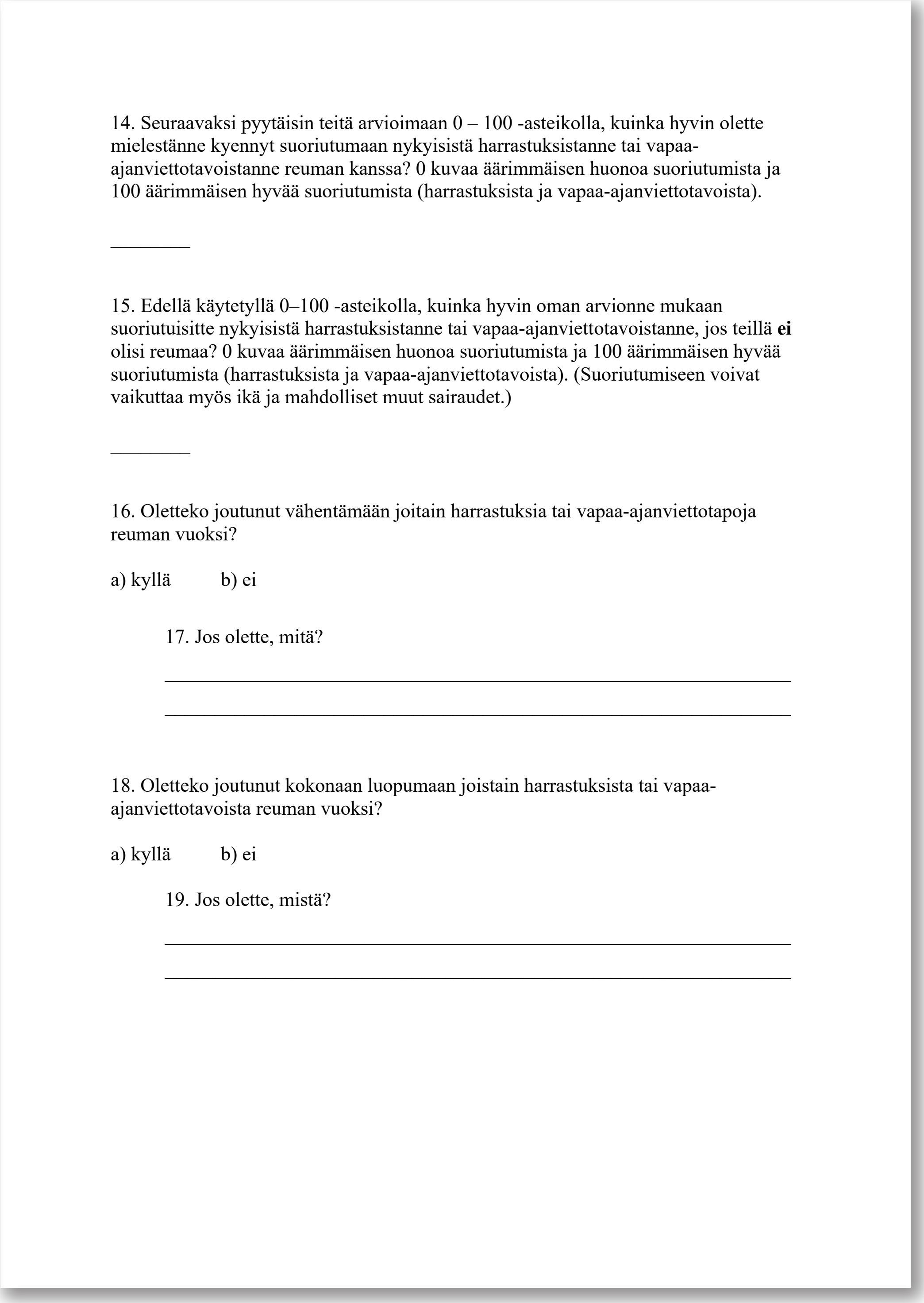
____

12. Kuinka monta **tuntia viikossa** käytätte arvionne mukaan aikaa näihin harrastuksiin tai vapaa-ajanviettotapoihin?

________ tuntia viikossa

13. Kuinka monta **tuntia viikossa** arvioisitte käyttävänne näihin mainitsemiinne harrastuksiin tai vapaa-ajanviettotapoihin, mikäli teillä ei olisi reumaa?

________ tuntia viikossa



14. Seuraavaksi pyytäisin teitä arvioimaan 0 – 100 -asteikolla, kuinka hyvin olette mielestänne kyennyt suoriutumaan nykyisistä harrastuksistanne tai vapaa-ajanviettotavoistanne reuman kanssa? 0 kuvaa äärimmäisen huonoa suoriutumista ja 100 äärimmäisen hyvää suoriutumista (harrastuksista ja vapaa-ajanviettotavoista).

____

15. Edellä käytetyllä 0–100 -asteikolla, kuinka hyvin oman arvionne mukaan suoriutuisitte nykyisistä harrastuksistanne tai vapaa-ajanviettotavoistanne, jos teillä **ei** olisi reumaa? 0 kuvaa äärimmäisen huonoa suoriutumista ja 100 äärimmäisen hyvää suoriutumista (harrastuksista ja vapaa-ajanviettotavoista). (Suoriutumiseen voivat vaikuttaa myös ikä ja mahdolliset muut sairaudet.)

____

16. Oletteko joutunut vähentämään joitain harrastuksia tai vapaa-ajanviettotapoja reuman vuoksi?

a) kyllä b) ei

17. Jos olette, mitä?

____

____

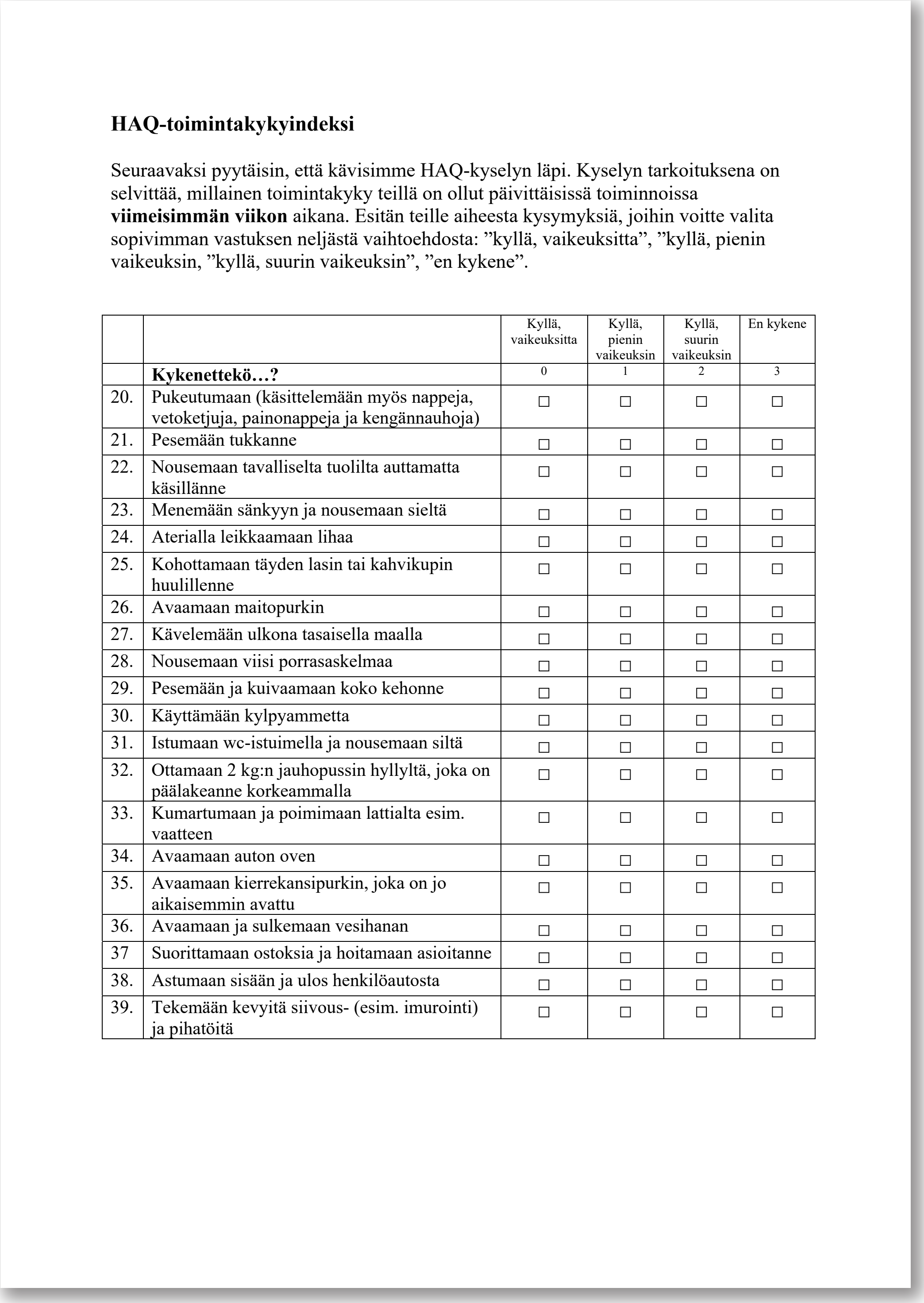
18. Oletteko joutunut kokonaan luopumaan joistain harrastuksista tai vapaa-ajanviettotavoista reuman vuoksi?

a) kyllä b) ei

19. Jos olette, mistä?

____

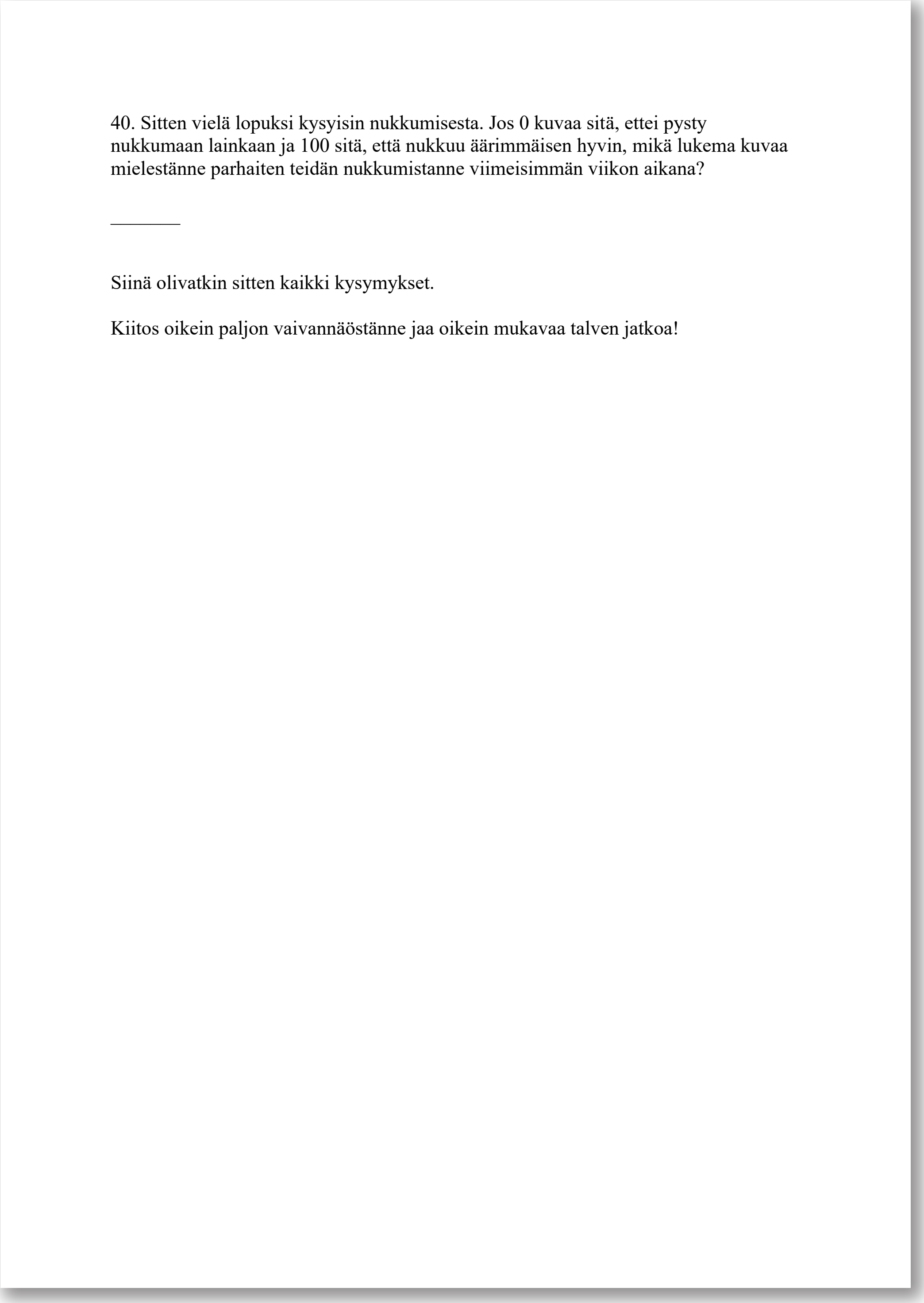
____



HAQ-toimintakykyindeksi

Seuraavaksi pyytäisin, että kävisimme HAQ-kyselyn läpi. Kyselyn tarkoituksena on selvittää, millainen toimintakyky teillä on ollut päivittäisissä toiminnoissa **viimeisimmän viikon** aikana. Esitän teille aiheesta kysymyksiä, joihin voitte valita sopivimman vastuksen neljästä vaihtoehdosta: ”kyllä, vaikeuksitta”, ”kyllä, pienin vaikeuksin, ”kyllä, suurin vaikeuksin”, ”en kykene”.

		Kyllä, vaikeuksitta	Kyllä, pienin vaikeuksin	Kyllä, suurin vaikeuksin	En kykene
	Kykenettekö…?	0	1	2	3
20.	Pukeutumaan (käsittelemään myös nappeja, vetoketjuja, painonappeja ja kengännauhoja)	☐	☐	☐	☐
21.	Pesemään tukkanne	☐	☐	☐	☐
22.	Nousemaan tavalliselta tuolilta auttamatta käsillänne	☐	☐	☐	☐
23.	Menemään sänkyyn ja nousemaan sieltä	☐	☐	☐	☐
24.	Aterialla leikkaamaan lihaa	☐	☐	☐	☐
25.	Kohottamaan täyden lasin tai kahvikupin huulillenne	☐	☐	☐	☐
26.	Avaamaan maitopurkin	☐	☐	☐	☐
27.	Kävelemään ulkona tasaisella maalla	☐	☐	☐	☐
28.	Nousemaan viisi porrasaskelmaa	☐	☐	☐	☐
29.	Pesemään ja kuivaamaan koko kehonne	☐	☐	☐	☐
30.	Käyttämään kylpyammetta	☐	☐	☐	☐
31.	Istumaan wc-istuimella ja nousemaan siltä	☐	☐	☐	☐
32.	Ottamaan 2 kg:n jauhopussin hyllyltä, joka on päälakeanne korkeammalla	☐	☐	☐	☐
33.	Kumartumaan ja poimimaan lattialta esim. vaatteen	☐	☐	☐	☐
34.	Avaamaan auton oven	☐	☐	☐	☐
35.	Avaamaan kierrekansipurkin, joka on jo aikaisemmin avattu	☐	☐	☐	☐
36.	Avaamaan ja sulkemaan vesihanan	☐	☐	☐	☐
37	Suorittamaan ostoksia ja hoitamaan asioitanne	☐	☐	☐	☐
38.	Astumaan sisään ja ulos henkilöautosta	☐	☐	☐	☐
39.	Tekemään kevyitä siivous- (esim. imurointi) ja pihatöitä	☐	☐	☐	☐



40. Sitten vielä lopuksi kysyisin nukkumisesta. Jos 0 kuvaa sitä, ettei pysty nukkumaan lainkaan ja 100 sitä, että nukkuu äärimmäisen hyvin, mikä lukema kuvaa mielestänne parhaiten teidän nukkumistanne viimeisimmän viikon aikana?

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Siinä olivatkin sitten kaikki kysymykset.

Kiitos oikein paljon vaivannäöstänne jaa oikein mukavaa talven jatkoa!

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