Hirsutism and Quality of Life with Aspects on Social Support, Anxiety and Depression
To my family
Hirsutism and Quality of Life with Aspects on Social Support, Anxiety and Depression
Abstract

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Hirsutism is excessive hair growth in women. The prevalence is estimated at 5%. The aim of this thesis was to describe different aspects of how life is affected for women suffering from hirsutism. Both qualitative and quantitative methods were used. Study I showed that hirsutism deeply affects women’s experiences of their bodies in a negative way and was experienced as a life sorrow. In Study II the patient-physician relationship was described. The patient-physician relationship from the patient’s perspective was suboptimal, as most meetings included feelings of being rejected and even humiliation. In Study III the aim was to translate and psychometrically evaluate an instrument that measures perceived social support, “The Multidimensional Scale of Perceived Social Support” (MSPSS). The translation was performed according to WHO:s official process, and validation was performed in a sample that consisted of 281 participants, 127 women with hirsutism (main sample) and 154 nursing students. MSPSS had good psychometric properties with regard to factor structure, construct validity, internal consistency and reproducibility. Study IV described different aspects of HRQoL in the main sample, the correlation of anxiety, depression, level of hairiness, age and BMI. The F-G scores were dichotomized into minor (F-G ≤14) and major (F-G≥15) hair growth. Higher levels of hair growth were significantly correlated to a lower level of QoL measured by DLQI, EQ-5D and symptoms of both anxiety and depression measured by HADS. Study V investigated if social support was associated with quality of life and outcome of HRQoL compared to a reference group of women (n=1115). SF-36, the MSPSS and the F-G scale were used. Compared to the reference group, women with hirsutism reported lower quality of life in all dimensions of SF-36 (p<0.01) The dimension most affected was vitality (VT=41.2), which had a lower value than has been reported for patients with MS and myasthenia gravis. A Multiple Regression Analysis showed a significant relation between quality of life and social support, indicating its importance for the ability to adapt, in spite of low quality of life.

Keywords: hirsutism, HRQoL, EQ-5D, DLQI, HADS, SF-36, MSPSS.

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Patient physician relationship
Social support
Social support's effect on health

RATIONALE FOR THE THESIS

AIM
Specific aims

METHODS

Study I
Participants
Setting
Data collection
Analysis

Study II
Participants
Setting
Data collection
Analysis

Study III
Participants
Setting
Data collection (procedure)
Translation
Analysis

Study IV
Participants
Data collection
Study measurement tools
EQ-5D
DLQI
HADS
The Ferriman-Gallwey scale
Analysis

Study V
Participants
Data collection
Study measurement tools
### ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>F-G score</td>
<td>Ferriman-Gallwey score</td>
</tr>
<tr>
<td>PCOS</td>
<td>Poly cystic ovary syndrome</td>
</tr>
<tr>
<td>DHEAS</td>
<td>Dehydroepiandrosterone sulfate</td>
</tr>
<tr>
<td>DHEA</td>
<td>Dehydroepiandrosterone</td>
</tr>
<tr>
<td>DHT</td>
<td>Dihydrotestosterone</td>
</tr>
<tr>
<td>CAH</td>
<td>Congenital adrenal hyperplasia</td>
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<tr>
<td>NCAH</td>
<td>Non classical congenital adrenal hyperplasia</td>
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<tr>
<td>SHBG</td>
<td>Sex hormone binding globuline</td>
</tr>
<tr>
<td>T</td>
<td>Testosterone</td>
</tr>
<tr>
<td>FAI</td>
<td>Free androgen index (FAI=Tx100/SHBG)</td>
</tr>
<tr>
<td>IGF</td>
<td>Insulin growth factor</td>
</tr>
<tr>
<td>OCP</td>
<td>Oral contraceptive</td>
</tr>
<tr>
<td>EE</td>
<td>Ethinyl estradiol</td>
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<tr>
<td>CPA</td>
<td>Cyproterone acetat</td>
</tr>
<tr>
<td>IPL</td>
<td>Intense Pulse Light</td>
</tr>
<tr>
<td>HRQoL</td>
<td>Health Related Quality of Life</td>
</tr>
<tr>
<td>DLQI</td>
<td>Dermatology Life Quality Index</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>Euroqol 5 Dimensions</td>
</tr>
<tr>
<td>SF-36</td>
<td>Short Form 36</td>
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<tr>
<td>HADS</td>
<td>Hospital Anxiety and Depression scale</td>
</tr>
<tr>
<td>MSPSS</td>
<td>Multidimensional Scale of Perceived Social Support</td>
</tr>
<tr>
<td>SD</td>
<td>Standard deviation</td>
</tr>
<tr>
<td>CV</td>
<td>Coefficient of variation (SD/mean)</td>
</tr>
<tr>
<td>ITC</td>
<td>Item Total Correlation</td>
</tr>
</tbody>
</table>
LIST OF PUBLICATIONS

This thesis is based on the following papers, which are referred to in the text by their Roman numerals:

I Ekbäck M, Wijma K, Benzein E. “It is Always on my Mind”: Women’s Experiences of Their Bodies When Living with hirsutism. *Health Care for Women International* 2009:30(5):358-72


IV Palmetun Ekbäck M, Lindberg M, Benzein E, Årestedt K “Health-related Quality of life, depression and anxiety correlate to the degree of hirsutism”. *Dermatology* 2013 Oct. [Epub ahead of print]

V Ekbäck M, Årestedt K, Benzein E, Lindberg M “Importance of social support for the quality of life among women with hirsutism” *In manus*

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INTRODUCTION

What is health and what is a disease? How is the disease interpreted by the patient and what effect does a chronic but benign skin disease have on a patient’s life? Disease is the medical term for a physiological malfunction. Illness is how the patient interprets the undesirable state when suffering from a disease. To live with a chronic illness affects a person thoroughly, as there are no understood differences between the body and the self. Thus a chronic illness also affects a person’s real self (1). Patients and doctors do not interpret a disease in the same way. In order to help the patient it is important both to understand the disease and the patient’s experience of the disease, the illness (2). Hirsutism i.e. hairiness in a male pattern way in a woman, is mostly of benign origin and yet seems to deeply effect woman’s well-being and quality of life.

The reason for my interest in this topic was one patient with hirsutism who attended the laser unit with her employer in order to get help. The employer said that the woman was a valuable employee, but she had often reported herself sick. The patient was both restrained and desperate at the same time. She told me how she had tried to get help from healthcare with the facial hairiness, which bothered her most. But she did not get any help at all, regarding information about lasers or medications. So she had taken the telephone book and looked up the yellow pages and then contacted every clinic that might have a laser for hair removal. Her old parents had helped her with money for laser treatment after she had a nervous breakdown in front of them. She told me how terrible it was to go to the dentist because of the bright light they use, thus making the hairiness more visible. The hairiness has hindered her to live a full life, she argued.

At that time hirsutism was not considered as a disease but purely a cosmetic problem by many doctors. I must admit that I had not given the problem any thought at all before I met the patient at the laser unit.
BACKGROUND

Hirsutism is an international issue and approximately 5 to 15 % of the general population of women are reported to be hirsute (3-6). Hirsutism is excessive growth of terminal hair in women, in skin areas sensitive to androgens. The areas most affected are the face and the lower abdomen (7). It is a sign of increased androgen activity on the hair follicles (8), either as a result of increased circulating levels of androgens or increased sensitivities of the hair follicles to normal circulating levels of androgens (8). Research on hirsutism to a great extent includes women with Polycystic Ovarian Syndrome (PCOS), of which hirsutism is a common symptom. Guyatt, Weaver, Cronin, Dooley, & Azziz, showed that excessive hair growth in women with PCOS was the second most serious rated factor after infertility that negatively influenced their quality of life (9), and Himelein & Thatcher found that these women had higher depression scores and greater body dissatisfaction than women without PCOS (10). Many women with hirsutism struggle with overweight, a common symptom beside hirsutism in PCOS (11). Elsenbruch et al. have argued that emotional distress and obesity decrease quality of life for these women. Previous research has shown that women with PCOS and excessive hair growth feel that they are abnormal and not proper women. However, women could have hirsutism without having PCOS or other disorders (12). Women with excessive facial hair growth experience it as a theft of womanhood (13) and talk about themselves in masculine terms, such as having ‘male hair’ or a ‘full beard’ (13, 14).

A brief physiology of hair

Approximately 5 million hair follicles cover the body. The hair follicles are mostly associated with a sebaceous gland (i.e. forming the pilo-sebaceous unit) (15). The hair growth has a three stage cycle: anagen phase (growth phase), catagen phase (involution phase) and telogen phase (resting phase) (16). Several growth factors are involved in the hair growth, for instance, insulin-like growth factor I and keratinocyte growth factor. An extended anagen stage and abnormal enlargement of the hair follicles lead to a hirsuid stage. The difference in gene transcription is the reason for the difference in hair growth on the body (4, 16, 17). Androgens are the most significant hormones in the hair growth modulation and are involved in keratinization, prolongation of the anagen phase and the stimulation of the
transformation of vellus hairs into terminal hairs in androgen dependent areas (16).

**Etiology of hirsutism**

Polycystic ovary syndrome (PCOS) is the most common cause of hirsutism (18), and is seen in 70% of hirsute women. PCOS is a syndrome with ovarian dysfunction, where the diagnosis is determined according to the Rotterdam diagnostic criteria, such as oligo-/or anovulation, clinical and/or biochemical signs of hyperandrogenism and/or polycystic ovaries (if other causes are excluded as: adrenal hyperplasia, androgen secreting tumors, Cushing’s syndrome, Acromegaly). Clinical manifestations of PCOS are: hirsutism, obesity, insulin resistance, acne and cardiovascular complications (19). Insulin receptors are present in the ovaries and insulin could bind to the Insulin Growth Factor (IGF). Insulin can then act as a co-gonadotropic and stimulate the androgen production in cooperation with Lutenizing Hormone (LH). Further, insulin stimulates the synthesis of oestrogen and progesterone, enhances ovarian growth and cystic formations, stimulates theca cells proliferation (where androgens are produced), activates the IGF-1 system and influences ovulation. There are some researchers who suggest that intensive insulin therapy may enhance the evaluation of PCOS in women with diabetes type I (20).

Idiopathic hirsutism is considered in 10 – 15% (21), and mostly considered as ethnic or genetic (22). However there is evidence that 40% of women who are considered to have idiopathic hirsutism and with a history of “regular” cycles in fact are oligo- or anovulatory (23). Other causes of “idiopathic” hirsutism could be abnormalities in the androgen receptor, increased peripheral activity of 5-alpha reductase in the hair follicle (6) or mild to moderate abnormalities in the steriodogenesis in the adrenal gland, the ovary or both (24). All women have production of androgens and the skin is hormonally active and could convert androgens to more potent variants. About 50% of testosterone is produced in the ovaries and adrenal glands. Androstendion, also produced by the ovaries and adrenals, could be converted to testosterone in the periphery.

Other not so common causes of hirsutism are: HAIR-AN (hyperandrogenism, insulin resistance, acne, obesity and acanthosis nigricans), SAHA (seborrhea, acne, hirsutism and acanthosis nigricans) (25), Congenital adrenal hyperplasia (CAH), an autosomal recessive inherited disorder, caused by an enzymatic defect in the biosynthetic pathway of cortisol and aldosterone (26) and the non-classical congenital adrenal hyperplasia...
(NCAH), caused by 21-hydroxylase (21-OH) deficiency. This disease can be presented with premature pubarche, hirsutism in the prepubertal years and primary amenorrhea, however hirsutism could be the only sign of the disease (27). Acromegaly, hyperprolactinemias and Cushing’s syndrome can also cause hirsutism. Important but rare cases are androgen-secreting tumours in the ovaries or adrenal glands. In these cases there is a rapid onset and progression of virilization. Medications that should be excluded as a cause of hirsutism are valproic acid, androgens and anabolic steroids and some progestins in oral contraceptives.

**Diagnosis of hirsutism**

A thorough medical history should include: menstrual history, onset and progression of hairiness, weight gain, on-going or previous treatments. A clinical examination should include: assessment of hairiness, a check-up for other cutaneous signs of hyperandrogenism, acne, seborrhea, acanthosis nigricans and hair loss, as well as evaluation of other causes for hirsutism such as Cushing’s disease, acromegaly or a thyroid disorder (28).

Laboratory testing of s-testosterone is not recommended for women with isolated and mild hirsutism, according to the American Endocrine Society guidelines “Evaluation and treatment in premenopausal women with hirsutism 2008”, because the likelihood of finding an underlying medical disorder that would change the management is not great. Testing for androgen levels are, on the other hand, suggested for women with moderate or severe hirsutism in cases with sudden onset of hairiness and rapid progression. It is also suggested for women with hirsutism with additional symptoms such as: menstrual irregularity, infertility, central obesity, acanthosis nigricans or clitoromegaly (29). Sex hormone-binding globulin (SHBG) is often lowered in women with PCOS and obesity. Patients with PCOS often have elevated free serum testosterone with increased luteinizing hormone (LH) and lowered follicle-stimulated hormone (FSH) (FSH/LH = 1:2 or 1:3) (18). Somatomedin C and prolactin are taken to rule out acromegaly (28, 29).

**Assessment of hairiness**

The most common method used is the visual scoring method, initially developed by Ferriman and Gallwey in 1961 (30). This method has been modified by Hatch, Rosenfield, Kim and Tredway 1981 (31). Nine body areas are sensitive for androgens, each is scored from 0-4 and then summed to get a total hair growth score. The maximal total score is 36
and a score of 6 is usually set as a cut-off score for hirsutism. A Ferriman-Gallwey score of 8 to 15 indicates moderate hirsutism and a score above 15 is considered as severe hirsutism (4, 6). The measurement of terminal hair on the chin or the lower abdomen with a Ferriman-Gallwey score ≥ 2 can be used to estimate the amount of total body hair (32). Objective methods for measuring hair growth are, for instance, photographic evaluations and microscopic measurements. However, these methods have weaknesses as well, photographs may differ in colour and women must let their hair grow in order to be evaluated.

The aim of medical treatment of hirsutism is to correct the hormonal imbalance and thereby stop further progress of hairiness and to reduce the amount of hair somewhat in order to improve the aesthetic appearance of the woman. Any medical treatment must continue at least 6 months for an evaluation of effect and about 9 months to become maximal. That is because of the long hair-growth cycle.

**Pharmacological therapy**

**Oral contraceptives (OCP)**
OCP are recommended as first line treatment. However it is not proven that OCPs reduce hairiness (29). OCP stimulates the production of SHBG from the liver, thereby increasing the binding capacity of androgens in serum, suppression of LH secretion and therefore androgen secretion, reducing the risk for endometrial cancer in women with PCOS (33). OCP contains a synthetic estrogen ethinyl estradiol (EE) in combination with a progestin. A non-androgenic progestin (dospiren, dioenogest or cyproterone) is preferable (18).

**Antiandrogens**
All antiandrogens must be combined with adequate contraception as there is a teratogenic potential with these medications. Spironolactone is considered as the first-line antiandrogen (34). It is well tolerated and as effective as many other pharmacological options. It exhibits dose-dependent competitive inhibition of the androgen receptor as well as inhibition of 5α reductase activity (35). This makes it a useful treatment also for idiopathic hirsutism. Effective doses are 100-200 mg a day, divided into a two dose regime. Side effects are: postural hypotension, increased diuresis and dizziness, menstrual irregularities and hyperkalemia (29). To start with a lower dose the first two weeks and to check electro-
lytes is advisable. An OCP could be used concomitantly as menstrual cycle regulation. In addition to that OCPs and spironolactone also have complementary antiandrogenic actions (18).

Cyproterone acetate (CPA) is a progestogenic compound with antiandrogen activity. The main effect is inhibition of the androgen receptor. CPA has a long half life and is therefore administered in a sequential way. Side effects are: menstrual irregularities, liver functional abnormalities, weight gain and depression (36). CPA is available in a lower dose (2 mg) in combination with ethinyl estradiol (EE), under the brand name of Diane.

Flutamide, inhibits the androgen receptor and reduces the synthesis of androgens (37) According to the Endocrine Society’s “Clinical Guidelines for Evaluation and Treatment of Hirsutism in Premenopausal Women 2008” it is not more effective than 100 mg spironolactone and the most feared side effects are hepatic toxicity and liver failure (38, 39).

Bicalutamide is a nonsteroidal pure antiandrogen, indicated for prostate cancer but has been used in half the dose for women with hirsutism due to PCOS (37).

**Enzyme inhibitors**

Finasteride, inhibits the peripheral conversion of testosterone to dihydrotestosterone (DHT), by inhibition of type II 5 alpha reductase and is approved for benign prostate hyperplasia. For women with hirsutism it has been used in doses from 1-7.5 mg (40, 41).

Eflornithine, was developed for systemic treatment of Human African Trypanosomiasis (HAT), West African sleeping sickness. Alopecia turned out to be a common side effect of its systemic administration (42). As a local preparation it is approved for facial hairiness. It inhibits ornithine decarboxylase in the hair follicle, leading to thinner, shorter, less pigmented hair and reduced speed of hair growth. The cream should be applied twice a day. The effect is seen after 8-10 weeks in about 70 % of the treated women (28, 40, 41). The hair growth returns back to baseline in 8-10 weeks if treatment is discontinued. Side effects are not common, but stinging irritation and contact dermatitis from the preservatives have been described.

**Insulin-lowering drugs**

Examples of insulin-lowering drugs are: Metformin, pioglitazone, exenatide, liraglutide, sitagliptin, vildagliptin, saxagliptin, and linagliptin. Reducing insulin levels pharmacologically attenuates both hyperinsuline-
mia and thereby hyperandrogenemia, but should only be used in case of concomitant Diabetes (29).

**Glucocorticoids**
Glucocorticoids, suppress the adrenal and thereby the adrenal androgens, but is restricted to women with hirsutism caused by NCAH (29).

**Gonadotropic-releasing hormone analogs (GnRHa)**
GnRHa is not recommended for hirsutism as there is insufficient evidence for efficacy in the treatment of hirsutism (3, 29, 37).

**Epilation**
Most women use some home-based treatments, such as shaving, electric epilating, cold or hot waxes or chemical epilation. These methods are cheap and easy to use. Side-effects are that all methods except shaving and chemical epilation are painful methods. All methods are often associated with some skin irritation and folliculitis. It is however a misunderstanding that shaving leads to more rapid and thicker hair growth. To minimize side effects, one could give the patients some tips and tricks, such as using a clean shaving blade, to swab with gauze soaked with a weak boric acid solution and to use a hydrocortisone cream to minimize irritation after epilation.

**Electro-epilation (Electrolysis)**
An epilation probe is introduced into the hair follicle and destroys the follicle by galvanic electrolysis (direct current) or by thermolysis (high-frequency alternating current). The results are very operator-dependent. The regrowth rate is about 40 % (41).

**Photo epilation**
Hormonal therapy is generally successful in stopping further progress of the disorder, but it has only modest effects in reversing the hair growth progress (15). Hence photoepilation or electrolysis is mostly needed in order to reduce the amount of hair. In treatment of hirsutism with lasers or Intense Pulse Light, the goals are to destroy the hair follicle and to reduce the hair shaft caliber, without destroying adjacent tissues, a process called selective photothermolysis.
Lasers
Laser stands for light amplification by the stimulated emission of radiation and begins when a lasing medium (a liquid, a gas, a crystal or a semiconductor) is excited by a photon. Laser light is monochromatic, coherent and collimated, has high irradiance as all the light is concentrated into a narrow spatial band leading to high radiant power per unit area. The laser light is transferred into heat when it is absorbed by a chromophore, thus destroying the target by thermal damage. Chromophores are substances that preferentially absorb light and could be melanin, haemoglobin or oxyhaemoglobin or exogenous tattoo ink. For hair removal melanin is the chromophore. Melanin absorbs light in the red and infrared range of the electromagnetic spectrum (600-1200 nm). The pulse width plays an important role in determining selective photothermolysis (43). The duration of the laser pulse has to be shorter than the thermal relaxation time of the hair follicle in order to minimize collateral thermal damage (15). The thermal relaxation time of the hair follicle is 40-100 ms for terminal hair follicles measuring 200-300μm. In order to destroy the hair follicle, both the bulb and the bulge need to be targeted. As the target is melanin, the best result is achieved if the skin is light and the hair is dark. To combine Eflornithine cream and laser seem to optimize the treatment result (44).

Long-pulsed ruby lasers (694 nm) were the first lasers to be tested for hair removal. However the lasers were not seen so effective and are not used so much for hair removal today. Other lasers that are used for hair removal are: Alexandrite (755 nm), Nd:YAG (1064 nm) and Diode (800-810 nm). Intense Pulse Light IPL emits polychromatic non-coherent light with wave-lengths from 400-1400 nm. For hair removal a filter that filters the wave-lengths below 525-550 nm is often used (45). In studies lasers and IPL have been found equally effective (45, 46). Today there are no devices that give permanent hair removal, however long-term reduction is possible to achieve. Multiple treatments are needed and with each session it is estimated that 15% to 30% of hairs are removed (47).

Weight reduction
Even if weight reduction is difficult to achieve its importance must be stressed in obese women with hirsutism. It decreases serum-insulin, ovarian androgen production and the conversion of androstenedione to testosterone and increases sex hormone-bindning globulin production and it has no side effects (48). Referral to a dietician may be needed to get a “food
plan”. A plan for physical exercise should also be included in the strategy for weight reduction, and a prescription of exercise could be an effective way of helping the patient.

**Quality of life**

When the term quality of life was born is not easy to determine. One of the earliest references addressing something that resembles a definition of QoL is when Aristoteles (384-322 BC) notes: “Both the multitude and persons on refinement...conceive “the good life” or “doing well” to be the same thing as “being happy.” in Nichomachean Ethics (49) Much later the term QoL was coined, as a political term in the early twentieth century and has attracted interest since the early 1960s (50). Lawton (1983)(51) suggested a theoretical model of quality of life as the “good life” which included psychological well-being, perceived quality of life, behavioural competence and the “objective” environment. Since then a lot of articles have been written concerning quality of life. Taillifer, Dupuis, Roberge and Le May evaluated theoretical models for Qol from 1965 to 2001. They found 68 different models (50)! Qol is still is a multidimensional construct, without a consensus definition (52). The term HRQoL is a combination of two other terms, namely Health and Quality of Life (QoL). Numerous definitions of both these terms have been presented over the years.

**Health**

The concept health is not clearly defined and has been given various meanings, i.e. it has several connotations. There are two main views on health that can be clearly distinguished, the biomedical and the humanistic views. According to the biomedical view health is when body and mind have no biomedical dysfunction, i.e. are functioning according to statistically normal patterns for human beings (53). The humanistic view is often said to be a more holistic view, where health often connotes well-being or ability (under reasonable circumstances) to function and achieve vital goals irrespective of having a biomedical dysfunction or not (53). The internationally most well-known and influential definition of health is the definition stated by the World Health Organization (WHO). The concept health is defined as” A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” (WHO 1948). A definition must be possible to operationalize, i.e. be able to be measure (54), which led the research-
ers to the QoL research area. WHO decided to develop an international measurement of QoL, the WHOQOL-100.

The World Health Organization Quality of Life Group (WHOQOL Group) has provided a definition of quality of life, while working with the questionnaire. Quality of life is defined as “An individual’s 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.”

Health Related Quality of life

In medical literature and research studies QoL is often referred to as Health Related Quality of life (HRQoL). According to Guyatt et al, the term HRQoL was introduced to solve the problem that QoL represents both medical and non-medical entities (61), as many researchers in the 1980s found the term QoL confusing. It can be noted that the terms QoL and HRQoL not have been found easier to define today and that the terms sometimes are used interchangeably. Another way to explain why the concept HRQoL was coined may be by quoting John E Ware: “To distinguish the new multidimensional conceptualization of health from the old (i.e. health in terms of death and disease), the term quality of life was adopted. It became fashionable to lump all measures that define health beyond traditional indicators of biological functioning into a single category of quality of life measures. However, quality of life encompasses standard of living, quality of housing and neighbourhood, job satisfaction, health and other factors. The goal of the health care system is to maximize the health component of quality of life, i.e. health status, also referred to as health related quality of life” (55, 56). HRQoL is a subjective based concept and tries to measure the impact a medical disease has on quality of life, from the patient’s perspective. The theoretical framework on HRQoL goes back to the definition of health by the WHO and the definition of HRQoL normally includes a physical, psychological and social domain. According to Ware (56) the terms HRQoL and health can be regarded as synonyms, if HRQoL is defined as physical, mental and social well-being and functioning. If there is a lack of consensus about the definition of QoL, health and well-being, the same is the case for HRQoL. The lack of consensus is a fact that has been discussed among researchers since the term was born, however without a solution yet.
Determinants of Health-Related Quality of life.
HRQoL is influenced not only by the disease itself but also by socio-demographic, psychosocial, lifestyle, biomedical factors and gender (57). Low socio-economic status, immigrant status, single statuses are all related to poorer QoL. However many of these determinants are interrelated and may be proxies for one another. Women often receive lower scores on HRQoL questionnaires than men. Negative emotions increase the risk of disease and give lower QoL. On the other hand a person’s coping ability, sense of coherence and perceived control over life lead to better QoL (58).

Measurement of HRQoL
Today there is an abundance of HRQoL instruments i.e. validated questionnaires and the Departments of Health in western countries have become more interested in patient-reported outcome measures (PROMs), as is the Department of Health in Sweden. HRQoL instruments belong to PROMs. HRQoL instruments are often a PROM in medical registration for biological treatments, but are not used in every-day clinical practice in Sweden. HRQoL instruments can be categorized as generic and specific instruments.

Generic instruments
Generic instruments can be divided into two groups: single item instruments (global questions) and health profiles.

Global questions
Single item questions (global questions) are often categorical in their form. For example quoting from the SF-36: “In general would you say your health is ...”? The opinions about single global items differ when it comes to reliability. Strictly speaking concerning statistics, reliability increases with the number of items. On the other hand a global single-item measure may be more valid of the concept of interest than a score from a multi-item scale (59, 60).

Health profile instruments
Health profile instruments attempt to measure a broader health status, i.e. all important aspects of HRQoL (61). This way of measuring HRQoL has been justified on the assumption that a broader measure of health status automatically includes the main areas in which health can affect a person’s life (62). Examples of widely used, well-known health profiles are: the
World Health Organization Quality of Life (WHOQoL-BREF), the EuroQol EQ-5D, the Short Form 36 (SF-36), the Nottingham Health Profile and the Sickness Impact Profile (SIP). With these instruments it is possible to make comparisons between different diagnoses and ill-health. The Short Form-36 (SF-36) is one of the most used generic instruments worldwide, and the EQ-5D is the measure of choice in health economic analysis (63).

SF-36
The SF-36 originates from a more comprehensive instrument used in the Medical Outcome study (MOS), by an American research group, under the direction of John Ware Jr. The original instrument contained 149 items and was based on the broad concept of health as defined by the WHO 1948. To make the instrument more user-friendly for routine healthcare, the instrument was shortened to 36 items and eight subscales. The shorter form has been extensively tested and evaluated and has been found to reach the same psychometric quality as the original form (64).

The eight subscales are:

- **PF**-physical functioning-limitation in performing physical activities such as bathing or dressing.
- **RP**-role physical-limitation in work and other daily activities.
- **BP**-bodily pain-bodily pain and if it is limiting.
- **GH**-general health-how the person perceives their own general health.
- **VT**-vitality-a feeling of being tired, worn out vs. feeling energetic.
- **SF**-social functioning-interference with normal social activities due to physical or emotional problems.
- **RE**-role emotional-limitations in daily activities or work due to emotional problems.
- **MH**-mental health-feeling happy or calm vs. nervous and depressed.

Scores for each subscale/domain is going from 0 to 100. The higher the score is the better is the health in that domain. The eight subscales are divided into physically (PF, RP, BP and GH) or psychosocially oriented scales (VT, SF, RE and MH) and could be brought together into two main components or summary scores, the physical (PCS) and the mental (MCS).
It is important to interpret PCS and MCS together with the eight sub-
scales, as it has been shown that the two main component scores are recip-
rocal. PCS will receive high scores not only if levels on the physically ori-
ented scales are high but also if levels on the psychosocially oriented scales
are low. The reverse is true for MCS (64).

SF-36 version 2.0 has been psychometrically evaluated by Taft, Karl-
sson and Sullivan in a Swedish setting (65). Changes included wordings for
some items, item response format (from two to five steps in RP and RE)
and item response lay out. The PF, RP and RE have acquired $\alpha >0.90$, and
there are fewer ceiling and floor effects (65). Alongside the SF-36 there are
shorter variants such as SF-12, SF.12 version 2.0, SF-8 and SF-6D. The SF-
6D, like the EQ-5D could be used in health economic studies as one could
calculate an index value.

Examples of different dermatological conditions and HRQoL outcome,
measured by SF-36 are given in table 1.
**Table 1.** Examples of different dermatological conditions and HRQoL outcome, measured with SF-36.

<table>
<thead>
<tr>
<th>Study</th>
<th>PF</th>
<th>RP</th>
<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
<th>n</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swedish population, survey</td>
<td>86.4</td>
<td>80.2</td>
<td>71.8</td>
<td>70.3</td>
<td>61.6</td>
<td>85.1</td>
<td>83.4</td>
<td>76.8</td>
<td>4875</td>
<td>Lindberg et al 2013</td>
</tr>
<tr>
<td>Psoriasis, clinic</td>
<td>77.2</td>
<td>64.5</td>
<td>62.7</td>
<td>60.7</td>
<td>54.7</td>
<td>80.8</td>
<td>67.0</td>
<td>71.1</td>
<td>234</td>
<td>Lundberg et al 2000</td>
</tr>
<tr>
<td>Psoriasis, severe, population</td>
<td>77.2</td>
<td>72.2</td>
<td>49.5</td>
<td>44.0</td>
<td>48.3</td>
<td>71.5</td>
<td>72.2</td>
<td>61.5</td>
<td>25</td>
<td>Lindberg et al 2013</td>
</tr>
<tr>
<td>Psoriasis, mild population</td>
<td>84.4</td>
<td>76.4</td>
<td>68.1</td>
<td>66.8</td>
<td>60.0</td>
<td>80.8</td>
<td>82.6</td>
<td>75.8</td>
<td>166</td>
<td>Lindberg et al 2013</td>
</tr>
<tr>
<td>Atopic dermatitis, clinic</td>
<td>85.1</td>
<td>66.7</td>
<td>66.2</td>
<td>62.1</td>
<td>57.0</td>
<td>81.0</td>
<td>74.0</td>
<td>73.2</td>
<td>132</td>
<td>Lundberg et al 2000</td>
</tr>
<tr>
<td>Handeczema, occupational clinic</td>
<td>85.2</td>
<td>55.8</td>
<td>59.1</td>
<td>69.8</td>
<td>58.2</td>
<td>81.1</td>
<td>74.0</td>
<td>73.6</td>
<td>100</td>
<td>Wallenhammar et al 2004</td>
</tr>
<tr>
<td>Handeczema, severe population</td>
<td>83.4</td>
<td>70.5</td>
<td>63.2</td>
<td>55.8</td>
<td>47.9</td>
<td>73.1</td>
<td>66.7</td>
<td>64.6</td>
<td>54</td>
<td>Bingefors et al 2011</td>
</tr>
<tr>
<td>Handeczema mild, population</td>
<td>85.4</td>
<td>79.0</td>
<td>69.2</td>
<td>66.0</td>
<td>56.8</td>
<td>83.3</td>
<td>81.5</td>
<td>73.8</td>
<td>312</td>
<td>Bingefors et al 2011</td>
</tr>
<tr>
<td>Ichtyosis, clinic</td>
<td>84.7</td>
<td>75.2</td>
<td>73.0</td>
<td>71.7</td>
<td>59.0</td>
<td>83.6</td>
<td>75.6</td>
<td>73.5</td>
<td>121</td>
<td>Gånemo et al 2004</td>
</tr>
<tr>
<td>Hirsutism, clinic</td>
<td>82.6</td>
<td>66.5</td>
<td>67.4</td>
<td>58.2</td>
<td>41.2</td>
<td>60.7</td>
<td>50.1</td>
<td>56.0</td>
<td>126</td>
<td>Ekbäck et al. present study</td>
</tr>
<tr>
<td>Women, reference sample</td>
<td>92.3</td>
<td>81.1</td>
<td>74.1</td>
<td>72.5</td>
<td>54.5</td>
<td>82.1</td>
<td>78.6</td>
<td>71.3</td>
<td>1129</td>
<td>Bingefors 2013, personal communication</td>
</tr>
</tbody>
</table>

PF=physical functioning, RP=role physical, BP=bodily pain, GH=general health, VT=vitality, SF=social functioning, RE=role emotional, MH= mental health
EQ-5D
The EQ-5D is formerly known as EuroQol, after the Euroquol group who developed the instrument (57, 66, 67). It is used worldwide in clinical trials and health surveys. The EQ-5D includes five items covering different domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each item has three response categories: no problems, some problems, and extreme problems. Each answer could be dichotomized into EQ-5D levels of no problems (i.e. level 1) and problems (i.e. levels 2 and 3) (68). A single summary index ranging from -0.594 to 1.0 can also be calculated based on the results of the five items by applying a formula that attaches weights to each of the levels in each item. Higher values imply better health. In total there are \(3^5 = 243\) possible combinations. Every combination has a “quality of life weight”, which means that the combination has been valued in relation to full health (using the Time Trade-Off method). People from the general population have been used for the valuation procedure. This procedure can be criticized as it is well known that healthy persons tend to rate their quality of life for fictitious diseases lower than patients with the actual disease do.

The EQ-5D also contains the EQ visual analogue scale (EQ-VAS). The EQ-VAS is used to assess the respondents’ own opinions on their present health status. The VAS scale is from 0-100, where 0 is the worst health status and 100 is the best. The development of the instrument was grounded in the theory that people have to weight up the very diverse attributes of health to determine which, on balance, seems best, it should be possible to elicit such overall valuations by some suitable investigatory method which generates a single index value for each health state (66).

EQ-5D has been used in economic evaluation of dermatological conditions and therapies in nineteen studies and one abstract during 2003 and 2012 (69).

Disease specific instruments
Disease specific instruments are designed to capture issues that are important to patients with a specific disease. These instruments are more sensitive to detect differences that arise as a consequence of treatment policies which are compared in clinical trials (49) Examples of disease-specific instruments are Quality of life in Epilepsy (QOLIE-89) and Pediatric Asthma Quality of Life Questionnaire (PAQLQ).
Instruments for specific aspects of QoL

The Beck Depression Inventory scale (BDI), and the Hospital Anxiety and Depression scale (HADS) are instruments for specific aspects of QoL. HADS could also be referred to a domain specific scale as the questions focus on the domains anxiety and depression (49).

HADS was constructed by Zigmond and Snaith in 1983 (70) to assess possible and probable anxiety and depression in non-psychiatric hospital outpatients. It is composed of fourteen items and two seven-item subscales, the HADS-A (anxiety) and HADS-D (depression). Each subscale has a maximal total score that is 21. Scores between eight and ten in the anxiety subscale indicate mild to moderate anxiety and scores over ten indicate a probable distress disorder. Scores between eight and ten on the depression subscale indicate mild depression and scores over ten indicate a risk for depression in need of medical treatment. The scale is well validated and widely used in different clinical situations (71).

Dermatology specific instruments

Dermatology specific instruments are designed for capturing the specific problems that skin diseases have on QoL. These instruments are designed to be applicable to all skin diseases, thus allowing for comparisons between skin diseases. In that way one could say that they are “generic” dermatological instruments.

Dermatology Life Quality Index (DLQI)

DLQI is the first dermatology specific instrument and intended for routine use. It was developed by Finlay and Khan in 1994 (72). It contains a 10-item questionnaire, based on the ten most common patient-reported aspects of having a skin disease. It was developed by letting 120 patients with different skin diseases, who attended the Dermatology Out-Patient Department at a University Hospital in Wales; describe the impact their skin disease has had on their life, during the last week. 49 different aspects were identified. Of those the most frequent reported aspects of quality of life impairment were chosen to a 10- items questionnaire. The questions were however phrased in a way so that they also encompassed the least frequently mentioned aspects of impairment. Minor adjustments were made after the pilot testing. The questionnaire has been psychometrically evaluated and been found to have a valid construct validity, high test-retest reliability and being responsive to changes. The responsiveness to even small but significant changes has been confirmed by other research-
The DLQI can be calculated as a total score, the maximum score is 30 (the higher the score the worse is the quality of life).

DLQI includes also six subscales: symptoms and feelings (possible score range 0-6), daily activities (possible score range 0-6), leisure (possible score range 0-6), work and school (possible score range 0-3), personal relationship (possible score range 0-6), and treatment (possible score range 0-3). Finlay and Kahn found no gender difference, but differences in mean DLQI scores for different dermatoses. The mean DLQI total score was 7.3. The mean DLQI score for healthy controls was 0.5 (72). In the Danish translated version there were similar results as in the original English version. Mean scores, internal consistency and test-retest reliability were comparable. The mean DLQI total score of the Danish outpatient sample of 7.9 was similar to the score of the original version (74). To facilitate the clinical interpretation of the DLQI scores, the grading or the banding has been developed by Hongbo and co-workers (75).

The meaning of the DLQI scores are: 0-1= no effect at all on patient’s life, 2-5 = small effect on patient’s life, 6-10 = moderate effect on patient’s life, 11-20 = very large effect on patient’s life, 21-30 = extremely large effect on patient’s life. DLQI is the most frequently used dermatology specific instrument today, used in over 50 000 patients in more than 80 languages (76). There has been some criticism about the DLQI’s unidimensionality, as DLQI misfits the Rasch model for psoriasis patients (77, 78). However Mork et al., received a one-factor solution for the Norwegian version using Factor analysis for psoriasis patients (79) and Mazzotti et al., found a homogeneous second-order factor underlying the four primary surface factors in psoriasis patients (73).

Health related quality of life in women with hirsutism.

Women with facial hirsutism have described it as a betrayal of womanhood (80). Sonino and Fava have evaluated quality of life in women with hirsutism and in a control group (women without hirsutism). They used the Kellner’s Brief Problem List (a self-rating scale that measure psychosocial problems), the Kellner’s Symptom Rating Test (SRT) (a scale that measures overall psychological distress, and anxiety, depression, somatic symptoms, anger-hostility, cognitive and psychotic symptoms), and the Marks’ Social Situations Questionnaire (SSQ), a scale that measure social phobia. Patients with hirsutism displayed significantly higher social fears at the SSQ than controls. They also showed more anxiety and psychotic
symptoms at the SRT, whereas there were no significant differences in depression, somatization, anger-hostility and cognitive symptoms (81).

Lipton et al found that unwanted facial hair was a great psychological burden for women and represents a significant intrusion into their daily lives. They suggested psychological support for women with hirsutism (82). Lo and Lanigan investigated the effect of laser treatment in 45 women with facial hirsutism. They used a modified DLQI before and one to two months, two to four months and six months after laser treatment in fifteen out of 45 women. The mean DLQI score before treatment was 12.8. The mean DLQI score at one to two months was 7.0, at two to four months it was 9.2 and at four to six months it was 11.5. There was a major improvement in DLQI score at 1-2 months but longer-term benefit was not observed when the hair growth has returned back to pre-treatment levels. In spite of that 70% of the women reported a high level of patient satisfaction and nearly 80% was willing to have further treatment (83).

Drosdzol et al evaluated the influence of hirsutism on general quality of life with the Short Form-36 Version 2, Hospital Anxiety and Depression Scale and Rosenberg Self-Esteem Scale. They found that hirsute adolescent girls scored statistically significantly lower on physical functioning, general health and social functioning than controls (adolescent girls without hirsutism). Anxiety was diagnosed in 26% in the group of hirsute girls as compared with 10% of the controls. The difference was statistically significant. They found also more problems of low self-esteem in hirsute adolescents compared with non-hirsute girls (14% vs. 2%) (84).

Guyatt, Weaver et al., (2004) showed that excessive hair growth in women with PCOS was the second most seriously rated factor that negatively influenced their quality of life (9). The changes that occur in women’s physical appearance as a result of PCOS, (such as obesity, acne and hirsutism), might contribute to psychological morbidity (9, 13, 81, 82, 136-139) and a feeling of being stigmatized (80).
Patient physician relationship

There are several models describing patient–physician relationships. In a literature review by Roter, three different models of such a relationship are described: paternalism, consumerism and mutuality. Paternalism is when the physician sets the agenda and makes decisions in regard to both information and services. The medical condition is defined in biomedical terms and the patient’s voice is absent. The opposite model is consumerism, where the patient sets the goal and agenda and is the one who exclusively and solely makes the decisions. The physician’s role is limited to a technical consultant. The medical encounter becomes more like a marketplace transaction (85). The optimal relationship model appears to be that of mutuality, also called relationship-centred, where the biomedical and life world perspectives are synthesized. Relationship-centred visits are medically functional, informative, facilitative, responsive and participatory (85). This is in line with a model by Hollnagel and Malterud (86) where patients’ “subjective” issues and physicians’ “objective” or biomedical agendas are integrated. They have evaluated the model and presented the awareness model in 2007. In that model, it is proposed that the physician’s agenda based on medical knowledge not only should be complemented by the patient’s agenda, but also by the physician’s reflections of own emotions. If the physician does not have a reflexive look at his or her own emotions, it is possible to create humiliations irrespective of having the best intentions (87), Figure 1.

Incorporation of the patient’s perspective into a relationship-centered medical paradigm has been suggested as appropriate for the 21st century as a way to optimize the interaction between the patient and the physician. The essence in the patient-centered method, developed by Joseph Levenstein, is that the physician should try to enter the patient’s world, to see the illness through the patient’s eyes (2).

According to Levenstein, the task of the physician is twofold: to understand the patient and to understand the disease (2).
The Awareness Model

Patient and doctor meet

Doctor explores parallel agendas

Doctor’s agenda
- Rationality
- Knowledge/experience

Emotions
- (doctor’s)

Patient’s agenda
- Rationality
- Knowledge/experience

Emotions
- (patient’s)

Mutual understanding

Figure 1. The Awareness Model, freely drawn after Hollnagel and Malterud.
Social support

Social support is a multi-dimensional concept with different definitions and ways of measuring it (88). Social support has been defined as assistance and protection given to others. It is hypothesized to be reciprocal, an exchange of resources between at least two individuals, i.e. it involves some kind of relationship transaction between individuals (89-91). According to Tardy, the best way to clarify differences in definition and approach to social support is to specify direction (support can be given and/or received), disposition (availability vs. utilization of support resources), description of support versus evaluation of satisfaction with support, content (what form does the support take?), and network (what social system or systems provide the support?) (92).

Social network refers to the structure of social ties and the web of relations that surround an individual including size, density and homogeneity (93). Zimet has pointed out that it is important to define how social support operates, the hypotheses and the dimensions: 1) direct versus buffering, 2) the nature of the support, 3) the focus of the curative effect of support, and 4) the action by which social support operates to enhance health (90).

Social support’s effect on health

Social relationships have been shown to predict a decreased risk for morbidity and mortality in a broad sense and have a positive effect on health (89, 94). Companionship or a social partner may reduce stress response and has not only an effect on the hypothalamic-pituitary-adrenocortical (HPA) system, but also on the sympathetic nervous system and the immune system (95).

The support can bolster the person’s ability to cope with imposed demands and thereby prevent a situation from being perceived (appraised) as very stressful. Secondly, it is supposed to reduce or even eliminate the affective reaction to a stressful event. The (HPA) system is sensitive to psychological stressors. It is further argued that social support has a buffering effect on stressful life events and depression (96) and that it has an influence on the neuroendocrine and immune functions (97). Perceived social support promotes self-esteem, which in turn has a positive effect on mental health (98). In addition, there is evidence that social support has effects on the cardiovascular response (99).

This is in line with the models that Cohen, Underwood and Gottlieb have created. The Main Effect Model describes how social support can
promote health and the Stress-Buffering Model how social support can influence responses to stressful life events.

Each individual interacts in different social relationships, for example with family and friends. When living with a life-long medical disease, the perceived support from these social relationships is of the utmost importance, as several studies have documented that social support has a great impact on the physical health outcome (100-102). On the other hand is it suggested that low social support has effect on cancer progression (103-105).

There are several scales based on the different theories, divisions, models, aspects and so on. It is not only the received support per se that is important but more how the support is perceived and also that the support is adequate for the situation. There are scales measuring perceived support and received support (106). Several scales are lengthy and complicated and different social relationships have different functions. Some researchers have found perceived social support to be a better predictor of psychological status than objectively measured social support (90, 107). The Multidimensional Scale of Perceived Social Support (MSPSS), developed in 1988 by Zimet, Dalhem, Zimet and Farley was intended to be short and easy to use, measuring perceived social support from different sources (family, friends and significant others), and to assess both perceived availability and adequacy of emotional and instrumental support. MSPSS is a widely used instrument (90). This instrument has three sub-scales: family, friends and significant others, measures social support from a subjective perspective, and is preferably short. The MSPSS has been found to be a reliable and valid instrument both in its original language (108) and in other languages (109, 110). The instrument is used in clinical and non-clinical settings (102, 111, 112), in various age groups (98, 113, 114) and in samples with various cultural backgrounds (115-117)
RATIONALE FOR THE THESIS

The first article about hirsutism was published in 1935. Since then only a few articles have been published in each decade. Since 1980 there have only been about a hundred articles a year, even if hirsutism is a common endocrinological complaint (40). The most common cause is PCOS, thus most of the articles focus on the medical aspects linked to PCOS (4, 20, 31, 33, 118). Hirsutism from a dermatological point of view is very little investigated. There are however some studies, addressing pharmacological and laser treatment e.g. (3-6, 8, 15, 17, 18, 22, 23, 29, 34, 35, 37, 41, 46, 47).

Research about HRQoL among women with hirsutism is very sparse. Three studies addressing the influence of hirsutism on HRQoL in relation to anxiety and depression have been found (81, 82, 84).

The literature is lacking in research that studies hirsutism in relation to body experience, social support, contact with healthcare and patient physician relationship. Even if hirsutism mostly is of benign origin, it is a chronic, non-curable disease. Hence there is a need of increased knowledge of how HRQoL is affected by hirsutism and how healthcare can support. Further it is of interest to compare HRQoL outcome in women with hirsutism in relation to other diseases.
AIM

The overall aim was to investigate and describe how women’s body experience, life and health-related quality of life is affected by living with hirsutism.

Specific aims

- Study I: to describe and interpret women’s experiences of their bodies when living with hirsutism.
- Study II: to describe how women with hirsutism experience their relationship with healthcare.
- Study III: to translate, adapt and psychometrically evaluate the Multidimensional Scale of Perceived Social Support for use in a Swedish context.
- Study IV: to describe different aspects of HRQoL, anxiety and depression in relation to level of hair growth among women with hirsutism, who had been in contact with healthcare for problems with excessive hairiness.
- Study V: The aims of the study were to, compare HRQoL between women with hirsutism and a Swedish normal population, and evaluate the social support reported by women with hirsutism using the new Swedish translation of MSPSS and to determine possible correlations between HRQoL and social support (MSPSS).
METHODS

Qualitative and quantitative methods are complementary. Qualitative data can generate hypotheses and reveal experiences that otherwise would have remained unknown. It is also possible to get a deeper understanding of phenomena. By using questionnaires and quantitative data it is possible to test a hypothesis in a bigger sample and to get an overview of the problem. For this reason both qualitative and quantitative methods have been used to investigate how it is to live with hirsutism, Table 2.

Table 2. Summary of the participants and the methods used in Study I–V.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Setting</th>
<th>Data collection</th>
<th>Analysis</th>
<th>Date of sampling</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Descriptive</td>
<td>10</td>
<td>Dermatology Department</td>
<td>Semi structured interview</td>
<td>Latent content analysis</td>
<td>June 2003</td>
</tr>
<tr>
<td>II</td>
<td>Descriptive</td>
<td>10</td>
<td>Dermatology Department</td>
<td>Semi structured interview</td>
<td>Descriptive content analysis</td>
<td>June 2003</td>
</tr>
<tr>
<td>III</td>
<td>Cross sectional</td>
<td>127+154</td>
<td>Departments of Dermatol. Private laser clinic A University in south east of Sweden</td>
<td>Questionnaire + interview</td>
<td>Descriptive statistics, Translation, Factor analysis, Construct validity, Reliability</td>
<td>October 2010-February 2011 (nursing students) October 2010 – August 2012 (main sample)</td>
</tr>
<tr>
<td>IV</td>
<td>Cross sectional</td>
<td>127</td>
<td>Departments of Dermatol. Private laser clinic</td>
<td>Questionnaire</td>
<td>Descriptive statistics, Correlation analysis</td>
<td>October 2010- August 2012</td>
</tr>
<tr>
<td>V</td>
<td>Cross sectional</td>
<td>127</td>
<td>Departments of Dermatol. Swedish population</td>
<td>Questionnaire</td>
<td>Descriptive statistics, Independent sample t-test, Multiple regression analysis</td>
<td>October 2010 – August 2012 (Main sample) (Reference sample published 2013)</td>
</tr>
</tbody>
</table>
Study I

Participants
Eleven women were invited to join the study and ten women accepted. The ages were between 17-53 years (md 30.5). Five women were married or co-habiting, two had a boyfriend and three were single. Six women were of Mediterranean origin and four were of Swedish origin.

The Ferriman–Gallwey score varied from 8–34 (md 21). Six women had irregular menstruation although not diagnosed with PCOS. Six women were treated with laser and all women used self-treatment.

Setting
The setting was a dermatology department at a university hospital.

Data collection
Women, who had been referred to the dermatology department for excessive hair growth and were interested in participating in an interview study, were given written and oral information. Exclusion criteria were inability to speak and understand Swedish or having a psychiatric illness. The open ended, semi-structured interviews followed an interview guide with three broad topics (119). The topics were: women’s experiences of their bodies, the impact on their daily life and contact with the healthcare system. All women were encouraged to talk as freely as possible about the problem. The interview lasted about 120 minutes, was tape recorded and transcribed verbatim.

Analysis
A latent content analysis described by Graneheim & Lundman in 2004 was performed (120). All interviews were read several times by the first author in order to become immersed in the data. Parts of the text that contained utterances of experiences of the body were extracted and organized as a new text and meaning units were identified, condensed and transformed into codes. The codes were then analysed in relation to the broader context i.e. the whole interview material. The codes were then interpreted into sub-themes and themes.
### Table 3. Some examples of the analysis

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s always in your head, in your mind … even if I don’t think that, you know, as soon as I see … get a funny look I think, like, “Oh, is it visible?” … that’s the first thing you think about. Even if you’re not thinking about it, it’s still there …</td>
<td>The hair is always there in one’s head, in one’s consciousness</td>
<td>Living with a pre-occupied mind</td>
<td>The body as a yoke</td>
</tr>
<tr>
<td>Probably no one who doesn’t have it herself can understand why you can’t eat the same things all the time. They don’t understand what is happening in the body. If I eat a lot of vegetables I lose weight. For this isn’t normal either. It’s not normal to have hair growth and actually it’s not normal to be on diets like this.</td>
<td>It is not normal to have hair growth and to be on diets of this kind</td>
<td>Living outside the female body norm</td>
<td>The body as a disgrace</td>
</tr>
</tbody>
</table>
Study II

Participants
The participants were same as in Study I

Setting
The setting was the same as in Study I

Data collection
The data collection was the same as in Study I

Analysis
In this study a qualitative descriptive content analysis was used, i.e. utterances about similar events, feelings and situations are put into the same category, but no interpretation of an underlying meaning is performed (121). Parts of the interviews that contained utterances about the medical care system were organized as a joint text. Then headings were written down to describe the content of all data and then aggregated to higher-order categories. Each interview was read again and related to the categories, to ensure that they covered all aspects of the data. Typical quotes for each category were then identified.

Establishing trustworthiness is fundamental in all research. In qualitative data the criteria for trustworthiness are: credibility, dependability, confirmability and transferability. Credibility deals with the focus of the research, and refers to confidence in how well data and processes of analysis address the intended focus. Dependability is a concept of consistency (data about a specific topic should be collected during as short a time period as possible; otherwise there is a risk of inconsistency of data). Confirmability/neutrality refers to the notion that the research should show that the results are grounded in data and not reflect the researcher’s own beliefs about a topic/phenomenon. Transferability refers to findings that are generally applicable, i.e. if the results could be transferred to other settings and groups.
**Study III**

**Participants**
The main sample consisted of 127 women, from an on-going observational study of health-related quality of life among women with hirsutism and the reference sample of 154 nursing students who were in the middle of a three year nursing programme. The majority of the nursing students were women. Only 18 out of 154 nursing students were men (11.7 %). Thus the majority of the informants (270/281) in the study were females.

**Setting**
The main sample was from two dermatology departments at university Hospitals, one in the south and one in the middle of Sweden, and one private laser clinic in the middle of Sweden. The reference sample was from a University in the south east of Sweden.

**Data collection (procedure)**
MSPSS is a widely used preferably short instrument (90), has twelve items, three sub-scales; family, friends and significant others and measures social support from a subjective perspective. It was developed by Zimet et al., in 1988 and has been found to be reliable and valid both in its original language (108) and in other languages (109, 110). The instrument is used in clinical and non-clinical settings (102, 111, 112), in various age groups (98, 113, 114) and in samples with various cultural backgrounds (115-117). Each item has a seven point Likert-type format (1= very strongly disagree; 7 = very strongly agree). The possible score range is between 12 and 84. The higher the score the higher is the perceived social support.

**Translation**
The translation and cultural adaption was carried out according to WHO:s official recommendations. Four researchers, two physicians and two nurses individually translated the instrument from English to Swedish. The differences were discussed in the group and an agreed upon Swedish version was then given to a bilingual person, familiar with both cultures and languages, who compared the both versions. An independent authorized translator performed the back translation from Swedish to English. The translated English version and the original English version were compared. There was a slight difference in wordings, regarding the translation of “a special person” to an important person in my life close by” (items
The differences was discussed with the constructor, who claimed that although those four items deviate from the original wording, they still have the same meaning.

The agreed upon version was pretested in a group of 30 Swedish nursing students, who also were interviewed about the comprehensiveness of the form. In addition to the MSPSS, the questionnaire also included questions about age, gender, having a partner and having children. The Swedish version of the MSPSS was given to the main- and reference sample (students). Students in one of the three classes were also asked to respond to the questionnaire once again one week after the first occasion. Of the 58 students who responded to the first questionnaire, 44 also completed the questionnaire after seven days.

**Translation process**

1. English version to Swedish
2. The translation versions were discussed in the group
3. The agreed upon Swedish version
4. A bilingual person “checked” the translated version and the original version
5. Back translation from Swedish to English by an independent translator
6. Discussion with the constructor
7. Pretesting the Swedish version in a pilot group
8. Final Swedish version

*Figure 2. Translation process*
Analysis
A description of the score distribution for items and scales was performed by item analysis. Homogeneity was evaluated by inter-item correlations and item-total correlations. Both tests are based on Pearson’s product-moment correlations. An acceptable level of the item-total correlations was set to r>0.3 (122).

An exploratory factor analysis with an orthogonal varimax rotation method (123), was conducted to evaluate the factor structure of the MSPSS. The factor analysis was first conducted on the main sample to evaluate if the original factor structure could be reproduced. Thereafter, the factor analysis was cross-validated in the reference sample to evaluate if the factor structure was stable during other conditions, i.e. in the group of nursing students.

Data for the women with hirsutism and nursing students respectively were first examined with Bartlett’s test of sphericity ($\chi^2 (66) =1662.1$, p<0.001 vs. $\chi^2 (66) =1711.4$, p<0.001) and with Kaiser-Meyer Olkin measure (KMO) in each item (0.86-0.93 vs. 0.80-0.90) and all items together (0.89 vs. 0.87). All these examinations indicated great sampling adequacy. The number of factors extracted was decided by the Kaiser criteria (eigenvalue >1.0) and controlled with Horn’s parallel analysis (124).

Reliability was evaluated according to internal consistency (Cronbach’s alpha with 95 % confidence interval) and intra-rater reliability (test-retest reliability) was evaluated for both item responses and scale scores. The items were evaluated by weighted kappa statistics ($K_w$), using linear weights for agreement (113). The scale scores were evaluated with intraclass correlations (ITC), for paired measurements (ICC, one-way model) and Lin’s concordance coefficients (CCC).To indicate adequate reproducibility for items, the following interpretation of $K_w$ statistics was used: poor (0.00-0.20), fair (0.21-0.40), moderate (0.41-0.60), good (0.61-0.80) and very good (0.81-1.00). Intra-class correlation should be beyond 0.7 to indicate satisfactory reproducibility (114).

Study IV

Participants
In total 200 women were identified through the medical records at the two university hospitals or by having on-going laser treatment at the private laser clinic. A total of 132 women (66%) returned the form, but five were excluded, because of wrong diagnosis in their medical record, incomplete form or psychiatric disease. The study population finally consisted of 127 women (which was the same sample as the main sample in study III).
It was possible to find and contact 55 out of 68 of the women who have not responded. The reasons they gave for not answering was: the questions were too private (15/55), eleven found the language to difficult and eleven said that they had forgotten to answer, four said that they did not have problem anymore, eight did not want to give a reason for not answering and five thought it was too time consuming to answer and one said that she did not want to answer the form.

**Data collection**

Data was collected by using questionnaires. The survey consisted of EQ-5D, Dermatology Life Quality Index (DLQI), the Ferriman Gallwey scale (F-G scale) for estimation of hair growth and socio-demographic questions (age, employment, education, civil status, BMI, income).

**Study measurement tools**

**EQ-5D**
The EQ-5D with five items and three levels, covering different domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression, was used (59). Each item has three response categories: no problems, some problems, and extreme problems. A single summary index ranging from -0.594 to 1.0 can be calculated based on the results of the five items by applying a formula that attaches weights to each of the levels in each item. Higher values imply better health. Each answer can also be dichotomized into EQ-5D levels of no problems (i.e. level 1) and problems (i.e. level 2 and 3) (68). Both methods were used in study IV.

The EQ-VAS scale where 0 is the worst health status and 100 is the best was used to assess the respondents’ own perception of their health status.

**DLQI**
The DLQI developed by Finlay and Kahn, (72) was used. It measures skin diseases’ impact on health-related quality of life, during the past week and consists of ten items, each with four response categories ranging from 0 (not at all) to 3 (very much). A total score can be calculated and includes six subscales: symptoms and feelings, daily activities, leisure, work and school, personal relationship and treatment. The clinical interpretation of the DLQI total scores is: 0-1 = no effect at all on the patient’s life, 2-5 = small effect on the patient’s life, 6-10= moderate effect on the patient’s life,
HADS
HADS constructed by Zigmond and Snaith to measure the level of anxiety and depression (70) was used. It has two seven-item subscales, the HADS-A (anxiety) and HADS-D (depression). Each subscale has a score range between 0 and 21. Scores between eight and ten in the anxiety subscale indicate mild to moderate anxiety and scores over ten indicate a probable distress disorder. Scores between eight and ten on the depression subscale indicate mild depression and scores over ten indicate a risk for depression in need of medical treatment.

The Ferriman-Gallwey scale
The hair growth was estimated according to the Ferriman-Gallwey scale (30, 31). Nine body areas are scored from 0 to 4 and the scores in each area are summed for a total hair growth score. The maximal score is 36. The F-G score can be categorized based on the following thresholds; F-G score 8-10 (mild hirsutism), F-G score 11-14 (moderate hirsutism), F-G score ≥ 15 (severe hirsutism) (118). In study IV, the F-G scores were dichotomized into minor (≤14) or major (≥15) hair growth.

Analysis
The analyses were performed using SPSS 21.0 for Windows (SPSS Inc., Chicago, IL, USA). Descriptive statistics (frequencies, per cent, mean, standard deviation) were used to describe characteristics of the participating women as well as the level of the study variables. Pearson correlation coefficients were used to explore the association between levels of hair growth (F-G scores) and HRQoL, anxiety and symptoms of depression. Independent sample t-test and Mann-Whitney U test were used to compare HRQoL, anxiety and symptoms of depression among women with minor and major hair growth.

Regarding HRQoL, anxiety and symptoms of depression, Cohen’s d effect size was calculated for the differences between women with minor and major hair growth. The effect sizes were interpreted as: d=0.2 small effect, 0.5 median effect, and 0.8 large effect. The level of statistical significance was set at p<0.05.
Study V

Participants
The main sample (n=127) same as in Study III and IV and a reference sample that consisted of 1 115 women from a nationwide population survey in Sweden concerning the consumption of pharmaceuticals related to self-reported diseases (including skin diseases).

Data collection
Data was collected by using questionnaires including SF-36, Ferriman-Gallwey scale, the MSPSS and socio-demographic questions (age, employment, education, civil status, children, BMI, income, satisfaction with work, social contact).

Study measurement tools

SF-36
The SF-36 was used to assess HRQoL (64). It contains eight different domains (aspects) of health related quality of life. Each domain are scored from 0 – 100. The higher the score the better is the HRQoL in that domain.

MSPSS
The translated version of MSPSS was used (90) for measuring the perceived social support. MSPSS has 12 items and seven-point Likert-type response format and three subscales (Family, Friends, Significant other). The possible score range is between 12 and 84. The higher the score the better is the perceived social support.

Analysis
Descriptive statistics (frequency, mean, standard deviation) were used to describe patients, demographic, clinical characteristics, level of social support and HRQoL.

Multiple linear regression analysis was used to explore the association between social support and HRQoL. Adjustments for covariates (age, hairiness and BMI) were made in the adjusted model. As the subscales of social support were highly correlated with one another (family, friends and significant other), the MSPSS total score was used in both the initial and the adjusted model to avoid problems with multicollinerarity.
Differences between the outcome of the eight dimensions of SF-36 in the study sample (main sample) and the reference sample were analysed by using an independent sample t-test (128).
ETHICAL CONSIDERATIONS

According to Swedish law SFS, 2003:460, and the changes in SFS, 2003:460 (SFS 2008:192), approval from the relevant ethics committee is also required for research which is accomplished with the help of registers, interviews and questionnaires. In addition, the changes to the legislation mean that all research that comprises treatment of so-called sensitive personal information is to be subject to an ethical review, whether or not the subjects of the research have explicitly given their consent. An application for Studies I and II was sent to the Ethics Committee of Örebro University Hospital (Dnr 288/02), even if it was not required for interview studies at that time. For Studies III-V an application was sent to the Regional Ethical Review Board at Uppsala University (Dnr: 2010/207).

In all of the Studies I-V the informants were informed of the purpose of the study and that the findings were to be published in scientific journals. Informants were assured that their participating was confidential and voluntary, and that they had the opportunity to withdraw at any time. They were also informed about how they could get access to their personal data. The informants also were given the possibility to address special questions regarding the actual study to the first author of the article. All informants gave their informed consent to participating after receiving detailed information. In Studies I-II the informants received fictive names in the beginning of the interviews. These fictive names were kept throughout the audiotaped interviews and the transcriptions and in the articles. In Studies III-V, the forms were number-coded, so the informants’ identity was removed. These code numbers were kept throughout the analysis.
RESULTS

Study I

Four closely connected themes emerged from the analysis: 1) The body as a yoke 2) The body as a freak 3) The body as a disgrace and 4) The body as a prison.

1) The body as a yoke comprises the sub-themes: 1a) Living with a preoccupied mind and 1b) Living with a life sorrow. Their preoccupied mind made it difficult for them to concentrate on other thoughts and activities. The life sorrow was expressed as, a suffering, a hell or an obstacle to a decent life. They felt that they had not been offered any choice in life and that they were victims of a cruel fate.

   Living with a life sorrow:
   
   It’s irrevocable…..I was given a life and this is what that life looks like.

2) The body as a freak includes the sub-themes: 2 a) Living in an invaded body and with a forced identity and 2 b) Living with an altered self. They felt as if their body was invaded by the unwanted hair. They considered themselves repellent, hairy, ugly, horrible, disgusting, and abnormal and some called themselves as being like animals. They experienced themselves as outsiders and their body had forced them to an unwanted identity. The altered self was expressed as, the excessive hair growth standing in the way of their real self and the person they once were and that they could no longer ‘be themselves’, but were forced to act in a way they neither recognised nor liked.

   Living with an altered self:
   
   “The day it disappears, I don’t know what I’ll do. I’ll probably be … I suppose I’ll be a completely different person. I can say that without any doubt at all.” (2)

Women who were married described their men as supportive, but that did not change their negative image of themselves. In social conversations, they were coloured by their own perception of themselves as horrible, dirty, abnormal and less worthy than others and this hindered them from participating on equal terms with others.

   “For then I always feel so violated [in conversations with others] and you always feel bearded and …” (9)
3) The body as a disgrace comprises the sub-themes: 3a) Living with shame and guilt about oneself as a person and 3b) Living outside the female body norm.

Living with shame and guilt about oneself as a person was expressed as being deeply ashamed of one’s body and a feeling of guilt even if they intellectually know that they could not help it. This shameful feeling made them withdraw from personal contact both with their intimates and with other people. They also felt ashamed in relation to the female body norm of today which they could not fulfil (i.e. being slim and hair free). The hairiness has to be kept as a complete secret for everyone. However being offered some treatment, released them from the burden of being responsible for their state.

“I feel that it’s my fault and the same time I know that I can’t do anything about it. (4)

“I don’t want to talk about this with anybody. I want to get rid of it all. That’s how I feel. (4)

4) The body as a prison comprises of sub-themes that show various ways to escape: 4 a) removing the hair 4 b) covering the body 4 c) using imagination and 4 d) contemplating suicide. The women had a strong need and desire to escape from their hairy unwanted body, in which they felt trapped. That was not possible so the alternative was to perform self-administered treatments of removing the hair and to cover the afflicted areas with clothes or make-up. The women also escaped physically by hiding from other people, for example not opening the door when someone called, especially if they were not prepared, i.e. waxed or shaved.

“I lock myself in the bedroom and shut the window and then I shave and shower and put on make-up, which I call putting on my face. I say that I’m putting on and taking off my face. That’s an expression I use.” (5)

One way of transcending the body was to use their imagination. Then they could visualize themselves like women with ordinary hair growth. They could also imagine themselves in relation to their ideal appearance and being in various life situations where they were appreciated and loved.

“In my imagination I think that when you marry you can put on anything at all. In my imagination I don’t have any hair.” (4)

The most dramatic way of escaping the situation was to consider the option of committing suicide, which some women had, as they thought of...
their situation as a never-ending imprisoned life. Some of them knew women with excessive hair growth who had taken their lives.

“I said, why should I live? Just to be sad and just to think about this [hair growth]. I want to die.” (8)

Study II
Each woman told of several meetings with the healthcare personnel, all regarding meetings with physicians. Most meetings included feelings of being rejected. The categories were: 1) a feeling of being rejected 2) a feeling of being ashamed of showing their hairy body to the physician 3) a feeling of being affirmed.

The category a feeling of being rejected had three sub-categories 1a) not being offered medical treatment 1b) being referred to self-treatment 1c) not being taken seriously.

1a) Not being offered medical treatment:
When meeting the physician, all women wanted to the physician to listen to them and offer them some kind of medical treatment. From the women’s perspective, their condition was a disease, i.e. a medical problem.

Most of the women had a strong belief that treatments were available but that the physician withheld information about these. Consequently, most of the women told about physicians that mostly did not fulfil their wishes. Instead they were referred back to self-treatment.

“For me this is a disease just like any other, that you can get help for. I think this should be a matter for the doctors.”

1 b) Being referred to self-treatment:
To be referred back to self-treatment was a sign of not being helped, as they already had used various kinds of self-treatment, which they found both costly and insufficient.

1 c) Not being taken seriously:
Most of the women told about not being listened to and instead being referred to another doctor without knowing why, an experience they interpreted as not being taken seriously. They felt that they were being shuffled back and forth in the healthcare system without any results that improved their situations.
2) A feeling of being ashamed of showing their hairy body to the physician:
   It was an effort to seek medical care as they had to let their hair grow in order to validate their claim that they suffered from excessive hair growth. Several women also described the fear of encountering unexpected situations, which would force them to seek healthcare and the shame this would cause.

3) A feeling of being affirmed:
   A few of the meetings recounted by the women were experienced as affirmative. For example Cecilia who received help from the healthcare system in the form of medication and laser treatment on her face. Mary, who got help to apply for money for depilation expressed her affirmation like this:

   “I felt confidence in him (the physician), and I think it might also have been that he really saw me and understood that I had a problem and then helped me to apply for the subsidy.”

**Study III**

The women with hirsutism were significantly older compared to the nursing students, median age 32.0 and 23.5 respectively. Having children was also significantly more common among the women with hirsutism compared to the nursing students. There was no great difference between the groups for living with a partner, 45% and 51% respectively

Item analysis: All item scores were negatively skewed with a ceiling effect. However all response categories were used. The items with the lowest scores belonged to the subscale MSPSS friends and the items with the highest scores to the subscale significant others. The inter-item correlation showed good homogeneity. Items belonging to the same subscale showed the strongest pairwise correlations. The item total correlations exceeded the critical value of 0.4 with good marginal (range between 0.65 and 0.78).
Table 4. *Item total correlations based on the main sample (women with hirsutism, n=127)*

<table>
<thead>
<tr>
<th>Items and scales</th>
<th>Subscales</th>
<th>ITC</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 There is a special person who is around when I am in need</td>
<td>SO</td>
<td>0.749</td>
</tr>
<tr>
<td>2 There is a special person with whom I can share my joys and sorrows</td>
<td>SO</td>
<td>0.759</td>
</tr>
<tr>
<td>3 My family really tries to help me</td>
<td>Fam</td>
<td>0.734</td>
</tr>
<tr>
<td>4 I get the emotional help and support I need from my family</td>
<td>Fam</td>
<td>0.773</td>
</tr>
<tr>
<td>5 I have a special person who is a real source of comfort to me</td>
<td>SO</td>
<td>0.775</td>
</tr>
<tr>
<td>6 My friends really try to help me</td>
<td>Fri</td>
<td>0.753</td>
</tr>
<tr>
<td>7 I can count on my friends with whom I can share my joys and sorrows</td>
<td>Fri</td>
<td>0.700</td>
</tr>
<tr>
<td>8 I can talk about my problems with my family</td>
<td>Fam</td>
<td>0.738</td>
</tr>
<tr>
<td>9 I have friends with whom I can share my joys and sorrows</td>
<td>Fri</td>
<td>0.723</td>
</tr>
<tr>
<td>10 There is a special person in my life who cares about my feelings</td>
<td>SO</td>
<td>0.739</td>
</tr>
<tr>
<td>11 My family is willing to help me make decisions</td>
<td>Fam</td>
<td>0.647</td>
</tr>
<tr>
<td>12 I can talk about my problems with my friends</td>
<td>Fri</td>
<td>0.721</td>
</tr>
</tbody>
</table>

Fam = Family, Fri = Friends, SO = Significant others  
ITC = Item-total correlation
Factor structure: The Factor analysis showed a three factor solution as in the original version both in the main and the reference sample. All items demonstrated factor loadings >0.7. The strongest factor correlations were demonstrated between the subscales Friends and Significant others for the women with hirsutism. In contrast, the strongest association was demonstrated between the subscales Family and Friends in the sample of nursing students.

**Figure 3.** Exploratory factor analysis, based on a principal component factor method.
Known group validity: According to Cohen’s effect size, there were clinically relevant differences between the main and the reference sample. The greatest differences were demonstrated for the MSPSS Friends (d=0.90, large effect).

Reliability: The internal consistency was high for all scales in both the main sample and the reference sample. The internal consistency was higher in the main sample compared to the reference sample, but no MSPSS scale demonstrated a Cronbach’s alpha value <0.9.

The test-retest showed that MSPSS produced item and scale scores with satisfactory reproducibility. Except for item 5 (Kw=0.58), all others demonstrated good (Kw=0.6-0.8) or very good (Kw=0.8-1.0) reproducibility. Also the MSPSS scales demonstrated good reproducibility according to the intra-class and concordance correlation coefficients (range between 0.89 and 0.92).

**Study IV**

In total 66% of the participants were working and 13% were studying. Half of the participants (51%) were married or cohabiting. The level of hair growth varied between 2 and 35 (mean 19±8) and hair in the face was reported by 87% of the women.

**DLQI**

The mean DLQI total score was 11.8±8.4. DLQI total score for women with minor hairiness (F-G score ≤ 14) was 6.2±5.6 and for women with major hairiness (F-G score ≥ 15) 14.7±8.2.

DLQI values compatible with a very large effect on the patient’s life (DLQI score 11-20) were reported by 35%, and extremely large effect (DLQI score 21-30) by 19.8%. Moderate or small effects on the patient’s life were reported by 13.5% and 21.4% respectively. No effects on the patient’s life were reported by 10.3%.

There were significant correlations between the F-G score and DLQI-total as shown in figure 4.
Figure 4. Scatterplot
There were significant correlations between the F-G score and the different dimensions of DLQI ($r=0.32-0.54$). Higher values on the F-G score were correlated with worse quality of life and the effect size was large (ES =0.8) for all domains except Treatment. In all items, women with major levels of hair growth scored significantly more problems compared to women with minor levels of hair growth as shown in figure 5.

**Figure 5.** Spider graph, DLQI on item level, women with minor and major hairiness. F-G score = Ferriman Gallwey score, self-evaluated hair growth
The mean level of the EQ-5D index was 0.73±0.27. There was a significant correlation between EQ-5D index and F-G score (r=-.18). Women with minor hairiness had an EQ-5D index that was 0.80 and women with major hairiness had an EQ-5D index of 0.69.

The mean level for EQ-VAS (61.1±22.6), where 42% scored their health as less than 50, 46% scored their health between 50 and 79, and 22% scored their health as 80 or higher. The correlation between level of hair growth and HRQoL was significant (r=-.20) and the comparisons between women with minor and major levels of hair growth showed that the latter group had the poorest HRQoL and the effect size was large.

Dichotomized EQ-5D dimensions showed that the women had least problems with mobility (11%), self-care (3%) and usual activities (15%). In contrast, problems with pain or discomfort and anxiety or depression were common, 48% respectively 67%.

**Anxiety and depressive symptoms**

The mean score for anxiety was 9.5±5.3. Levels compatible with mild to moderate anxiety (HADS-A= 8-10) were reported by 17% while 37% reported levels indicating a probable distress disorder (HADS-A > 10). The mean score for depressive symptoms was 6.5±4.6. Levels indicating mild depression were seen in 48% of the women (HADS-D =8-10) and 16% had levels indicating a risk of depression in need of medical treatment (HADS-D >10). Levels of hair growth were significantly correlated with both anxiety (r=.18) and symptoms of depression (r=.20) and women with major levels of hair growth scored significantly more problems. The effect size was medium (ES=0.5).

**Study V**

A total of 68 (53 %) women from the main sample were satisfied with the contact they had with family, friends and workmates, while 54 women (47 %) wanted more contact with family, friends and workmates.

Women with hirsutism scored significant lower than the women in the Swedish reference sample in each dimension of SF-36 (Table 5). The dimension with the highest score for women with hirsutism was PF (82.6) but compared to the reference population (PF=92.3) this was a significant lower score. The dimension with the most marked depression was VT= 41.2.
The perceived social support measured with MSPSS revealed a mean total score of 62.2 ±18.1 for the group. Of the three subscales, the highest mean score was found in the subscale Significant others (22.7±6.6). A mean of 21.2±7.0 was reported for the subscale Family while the subscale Friends had the lowest mean score, 18.3±8.0. Scores lower than 15 were reported on the subscale friends by 33%, on the subscale family in 19% and, 12.7% reported a lower score than 15 on the subscale significant other.

Multiple regression analysis revealed a significant correlation between perceived social support and HRQoL. In the initial model, social support (MSPSS total score) was significantly associated with all sub-scales in SF-36. This association remained also after the adjusting covariates were included in the final model.

Table 5. SF-36 subscale scores, women with hirsutism and a female Swedish reference group

<table>
<thead>
<tr>
<th>SF-36 sub-scales</th>
<th>Hirsute clinical sample Mean (SD)</th>
<th>Reference group Mean (SD)</th>
<th>n</th>
<th>P-value compared to hirsutism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning (PF)</td>
<td>82.6 (21.5)</td>
<td>92.3 (14.3)</td>
<td>126</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Role-Physical (RP)</td>
<td>66.5 (36.8)</td>
<td>81.1 (32.7)</td>
<td>124</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Bodily Pain (BP)</td>
<td>67.4 (29.8)</td>
<td>74.1 (25.8)</td>
<td>126</td>
<td>&lt; 0.0062</td>
</tr>
<tr>
<td>General Health (GH)</td>
<td>58.2 (24.2)</td>
<td>72.5 (22.4)</td>
<td>126</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Vitality (VT)</td>
<td>41.2 (22.7)</td>
<td>54.5 (23.1)</td>
<td>126</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Social Functioning (SF)</td>
<td>60.7 (32.8)</td>
<td>82.1 (23.4)</td>
<td>126</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Role-Emotional (RE)</td>
<td>50.1 (43.4)</td>
<td>78.6 (35.1)</td>
<td>123</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Mental Health (MH)</td>
<td>56.0 (24.2)</td>
<td>71.3 (20.1)</td>
<td>126</td>
<td>&lt; 0.0001</td>
</tr>
</tbody>
</table>
DISCUSSION

The overall aim with this thesis was to investigate and describe how women’s body experience, life and health-related quality of life were affected by living with hirsutism. Other aims were to describe how women with hirsutism experienced their relationship with healthcare, to translate and psychometrically evaluate the MSPSS, to describe different aspects of HRQoL, anxiety and depression in relation to level of hair growth and to compare HRQoL between women with hirsutism and a Swedish reference sample and determine possible correlations between HRQoL and social support. To achieve that both qualitative interview studies and questionnaires were used.

Important findings were that the self-rated health status measured with EQ-VAS was seriously affected by the level of hair growth and so was the level of vitality. The mean level for EQ-VAS was (61.1±22.6) and 42% of the women scored their health as less than 50 (Study IV). The higher the FG-score was the lower was EQ-VAS. The vitality score was severely lowered as the mean for the group was 41.2 (Study V). This is important as it has been shown that there is correlation between the perceived health status and the consumption of healthcare and the experience (belief) of suffering from an illness and the level of vitality (64).

Another finding (Study I) was that living with hirsutism means living with a preoccupied mind and a life sorrow. As the women considered their state as a life-long condition, their sorrow could be compared with the term chronic sorrow as described by Burke, Eakes, and Hainsworth (129). The most common trigger of chronic sorrow is to compare oneself with current norms and find oneself as divergent. The hirsutism affected the women not only on a bodily level, but also on a social and mental level. The affected body level was for instance the necessity to constantly remove the hair and cover the body. The mental level was the preoccupied mind, the forced and changed identity because of their body, their secret (the hairiness) that has to be kept, the “transcending” of the body by using imagination. An example of the social level is being ashamed of the body and oneself in social situations. Social interactions such as conversations were influenced by the sensation of being less worthy than others and not being able to take part in many social activities. Their body image was negatively coloured, as they could not fit in with the female body norm and that made them feel stigmatized (Study I). This has also been shown for visible psoriasis, where the altered body image has a psychosocial im-
pact on the patient (130). The body image is not a stable state, but an interpersonal on-going process that is dependent on reflected appraisal (how we perceive that others view us), feedback on physical appearance and social comparisons (to compare one’s physical appearance to others) (131). To compare oneself with others and find oneself as divergent is both a trigger for chronic sorrow and a trigger for feeling stigmatized. A visible mark has a negative impact on a person’s mental health. If an individual has a feature or an attribute which attracts negative attention, others may turn away from that individual and deny fellowship (132).

In healthcare the term stigmatization is defined as having a discrediting mark which prevents the formation of normal relationships and leads to social discrimination and alienation (133). Skin diseases and defects are frequently the cause of social rejection; they are easily seen and often wrongly categorized as contagious by many people. The ironic thing is that contagious skin diseases often are curable, in opposite to chronic, non-contagious skin diseases. The women felt stigmatized and it required a great deal of courage for the women to seek healthcare (Study II). When doing so they also had to let the hair grow in order to validate their claim that they suffered from excessive hair growth. Mostly the women felt rejected by the physician when they were not informed about, or offered, any medical treatment. It seemed to be crucial for them to be confirmed as having a medical problem and thus at least have the opportunity to discuss some medical treatment with the physician. These results are in line with what has been found in an interview study by Kitzinger and Willmot, with women with PCOS. In that study many participants talked about the anger and the frustration about delays in diagnosis and lack of information provided by health professionals, which was experienced as a general unwillingness to take their symptoms seriously (13). The meetings where the women (Study II) felt rejected are in line with the description of a paternalistic meeting (85). As was evident from some interviews, such a meeting may also have elements of humiliation irrespective of having the best intentions (87).

The women considered femininity to be a part of their identity and to be hairy was a betrayal of their identity as women and made them feel less worthy than other women (Study I). The feeling of facial hairiness as a betrayal of womanhood has also been shown by Kitzinger (13). The women were aware that their body and experienced “self” differed from what they saw as their own body and their real “self”. Consequently, they talked about themselves in a depreciatory way, such as being ugly, horrible, dis-
gusting, and shaggy or being a hairy ape. This has also been found in other studies by Kitzinger, Willmot and Keegan (13, 14, 80). The way of labeling themselves affected not only their self-esteem negatively but also how they thought about themselves, as less worthy than other women. This is in line with a study by Keegan et al., where 60% of the women thought that hair growth had an impact on their view of themselves and when asked to specify gave examples as: feelings of being unfeminine, feelings of being unwomanly, feelings of being unattractive or ugly, reduced self-confidence and worries about others noticing the hair-growth (80).

A majority (70%) of the women were gainfully employed to the same extent as the female general population in Sweden, and most of them were working daytime (Study V). However they did not participate in social activities outside the work with workmates, in case they risked revealing their hairiness because of the embarrassment and guilt they felt over their situation (Study I). These “social fears” that the women with hirsutism feel are also described by Sonino and Fava (81). DLQI on an item level (Study IV) further strengthens the findings in the interview study, as the DLQI item with the highest score was embarrassment and self-consciousness. Half of the participants (51%) were married or cohabiting and some of the women acknowledged their partners for being supportive (Study I), but that did not seem to affect their body image.

However the social support from their partner is probably very important for their coping with the situation, and all the dimensions in SF-36 were correlated to social support (Study V). Social support explained 15-38% of the variance in HRQoL. One coping strategy in the striving for normality was the never ending self-treatment that was time consuming, expensive and painful, but was done in order to be able to be outside in society. The importance of social support for HRQoL has also been proven in psoriasis patients where social support was associated with higher quality of life and lower depression levels in women. For men the most prominent factor was a higher acceptance of living with the disease. However women seem to be more prone to depression than men (134).

A large proportion of the women reported anxiety and depression on HADS and in the anxiety and depression dimension with EQ-5D (Study IV). In the EQ-5D anxiety and depression dimension, problems were seen in 67%. Levels indicating mild depression were noted in 48% of the women with HADS and 16% had levels indicating a risk of depression in need of medical treatment. Levels compatible with mild to moderate anxiety were reported by 17%, and 37% had levels indicating a probable distress
disorder. Levels of hair growth were significantly correlated with both anxiety (r=0.18) and symptoms of depression (r=0.20). As living with excessive hair growth caused the women tremendous emotional distress, some had even thought of committing suicide (Study I). The comparison between minor and major hair-growth showed that women with major levels of hair growth scored significantly more problems with anxiety and symptoms of depression compared to women with minor levels of hairiness. Anxiety was however the most pronounced symptom. This has also been described by Lipton and Sherr where a majority in their sample of women with facial hirsutism displayed anxiety (82). Drosdzol et al., evaluated 50 adolescent hirsuid girls and compared them with a control group of young girls without hirsutism. They diagnosed anxiety in 26% of the group of girls with hirsutism compared to 10% in controls. In contrast to our study, they could not find correlations between level of hair-growth and QoL indices. However the mean F-G score in their group was 10.98 (compatible with mild hirsutism) and the mean F-G score in our group of women was 18.8 (compatible with severe hirsutism). Sonino and Fava also found more anxiety in the group of women with hirsutism compared to controls (81).

This mental preoccupation, the anxiety and depression might be contributing factors to the low level of vitality that was found in the vitality domain in SF-36 (Study V). The level of vitality was surprisingly lower than what has been reported for patients with myasthenia gravis and multiple sclerosis (135). The vitality stands for how energetic or how tired or exhausted a person feels. According to the Swedish norm data for SF-36 in the Swedish population (n=8930), the vitality level seems to be stable in the different age groups, except in the oldest age groups (SF-36 Health Profile Instrument, Swedish manual and interpretation guide) (64). The level of vitality was round 70 for women throughout the age groups, with a dip from 65-69 years old. The vitality level was lower for women with hirsutism than the Swedish norm data even in comparison with the oldest women (75+). There seems to be a correlation between the vitality item and disease experience, i.e. a low level on vitality corresponds to disease experience. In the health survey that was performed in Sweden during 1991-1992 in order to translate, culturally adapt and psychometric evaluate the Swedish version of SF-36, questions regarding disease experiences were posed to a population in a suburb to a bigger town (n= 651). People who responded that they often had felt sick during the last three months showed low values on the vitality score (64).
In Study V all the dimensions in SF-36 were lower in the group of women with hirsutism than in the reference sample. However the items belonging to the mental component score MCS were most depressed.

Adaptation to living with a chronic disease encompasses a range of phenomena: e.g. quality of life, emotional well-being, and acceptance of a life with a chronic disease in order to be able to participate in society (134). To be able to adapt to a different life, caused by the disease, the individuals need to develop psychological mechanisms enabling them to cope with the disease in the best possible way. Social support could be one contributor to the adaption to a live with a chronic disease and a factor that affects the outcome of HRQoL. In Study IV it was obvious that although hirsutism caused marked impairment of HRQoL and anxiety and depression, the women with hirsutism worked as much as women without hirsutism in Sweden, and mostly daytime (140). Social support might be of importance for this. It is a factor known to influence health and to influence outcome such as anxiety and depression in a variety of chronic diseases (141-143). It could be that the quality of the social support among women with hirsutism determines how well they can cope with their situation and adapt in social situations. The association between social support and HRQoL was shown in Study V. There were significant correlations between all dimensions of SF-36 and MSPSS, also when age, hairiness and body mass index were introduced as co-variates. This implies that social support might improve the self-reported HRQoL in women with hirsutism.

For evaluation of the social support (in Study V), the Multidimensional Scale of Perceived Social Support (MSPSS), was chosen as perceived social support seemed to be most important (145). In the translation and validation study (Study III) the Swedish version was found to be a psychometrically sound instrument to use. That indicates that the results in Study V, where social support was found to be important for HRQoL in women with hirsutism were trustworthy.

**Methodological discussion**

This thesis has both a qualitative and a quantitative approach, as they are complementary. Qualitative design is suited for exploring differences in a group and to find underlying meanings. A weakness is that you cannot generalize “quotations”. To be able to generalize data you have to use questionnaires.
The qualitative studies

Qualitative research could be hypothesis generating and means to describe rather than to prove (121). Qualitative methods are suitable in studies where the aim is to discover how people perceive the world. In qualitative analysis, knowledge is developed from experiences by describing and interpreting and summarizing the organized empirical data (146).

Studies I and II were qualitative descriptive studies. The sample was strategically selected and consisted of women of different ages, with different civil status and origin as it is important in qualitative studies to have a diversified group.

The interviews followed a semi-structured interview guide to ensure that all topics were covered, but at the same time one is freer to change the order of the questions, reformulation of questions and to use clarifying questions. It is also possible to let the informants speak more freely. If very structured and overly detailed interview questions are used there is a risk that the answers reflect the pre-understanding of the researcher rather than the informant’s view of the phenomenon that should be studied (147). The interviewer (ME) posed open-ended questions, which allowed the informants to answer more freely and the interviews were tape-recorded and transcribed verbatim.

Content analysis is rooted in communication theory and deals with manifest or latent content in a text (120), but there is no philosophical framework, which needs to be dealt with. Instead the importance is what the text says. In latent content analysis as was used in Study I, an interpretation of the latent content is made, and themes and sub-themes are formed during the analysis. The focus is on the subject and the context and what the underlying meanings of the text are. In Study II utterances regarding patient-physician relationship were extracted from the whole interview and organized as a new text, thus data were not as rich as in Study I. A manifest content analysis was more suitable, where the interpretation is "closer" to the text, and the text is organised and presented in categories (121).

Trustworthiness in Study I and II

How is trustworthiness achieved? Credibility (if data and analysis address the intended focus), was enhanced by choosing participants for the interview studies of both Nordic- and non-Nordic origin, of different ages and socioeconomic backgrounds, also the richness in data, the dialogue between researchers, the use of quotations and thorough description of the
research process (148). Dependability (stability, the degree to which data change over time), was enhanced by collecting data during two weeks, in the same setting and by using an interview guide. Transferability, i.e. the extent to which the findings can be transferred to other settings or groups, is highly dependent on the sample and context and should at the end be decided by the readers of the studies. To facilitate the enhancement for the reader, a description of the participants and the collection process was done (120). However, the result of a qualitative study, based on in-depth information from a strategically selected study group, can be tested in other contexts in order to validate the result (149).

The quantitative studies
The data used in the quantitative part of this thesis (Studies III-V), were collected by using cross sectional design. This means that data were collected from a respondent upon one occasion only. However data for the main sample (women with hirsutism) were collected from three different centres in Sweden and only well-established instruments were used. A weakness of the quantitative part of the thesis is that a non-randomised approach was used. Thus there might be sources of error, which might bias the results and the conclusions provided. Bias is any systematic error in the data and occurs as two major categories. Selection bias stems from study participants and information bias stems from errors in the information collected from participants (e.g. missing data in clinical registrations) (49) and social desirability bias (150). The study sample consisted only of women who had attended a dermatological clinic and this could of course be a source of selection bias. According to information bias there were very few missing items in the questionnaires and the response rate was over 60%. There is also evidence that self-reported information has less social desirability bias than interview bias (150).

In Studies III-V both parametric and non-parametric methods were used. The scale scores were treated as continuous variables and the items as ordinal data in the analyses. In Study III the items were evaluated by weighted kappa statistics. In Study IV, non parametric methods were used for the items in the spider graph and Pearson’s correlations were used for the bivariate analysis in Study IV. It could be questioned if the scales in questionnaires are continuous variables. However, Spearman’s correlation showed similar results. A multiple linear regression analysis was used in Study V as it has been shown that studies with more than 100 persons are fairly robust against violations of non-normality (151).
Study III was a translation- and validation study of a questionnaire measuring perceived social support. Translation and cultural adaptation of the MSPSS was carried out according to WHO: s official recommendation of translation and adaptation of research instruments (152).

This implies a “conceptual” equivalence rather than literal translation (153). Four researchers, two physicians and two nurses individually translated the instrument from English to Swedish. These versions were discussed in the research group and a decision on an agreed-upon version was made. The cultural adaption has been carried out with the help of a bilingual person familiar with both cultures. The Swedish agreed-upon version differed slightly in one dimension/subscale” Significant others”, but the difference was discussed with the constructor, who claimed that the Swedish version has conceptual equivalence. In that dimension the items 1, 2, 5, & 10, “a special person” was back translated as “an important person in my life close by”. It is possible that this translation makes it difficult to distinguish items from the subscale “Significant others” with the items from the subscale “Friends” and “Family”. However the factor analysis reproduced a three factor solution as in the original version and thereby strengthen that the translation and the adaptation of the instrument was carried out according to the rigorous process that also is recommended by the WHO.

There are two main aspects of validity: internal validity and external validity. Internal validity deals with the extent to which the results of an investigation accurately reflect the true situation of the study population. Extern validity is the extent to which the results of a study are applicable to other populations (154). Intern validity could be further divided into content validity (Does the questionnaire include the right questions for covering the dimension it is intended to measure?), construct validity (the assessment of the degree to which an instrument measures the construct that it was designed to measure), criterion validity (refers to correlations between an instrument and the true reality or against some other accepted standard) (49). In Study III we used an exploratory factor analysis based on a principal-component factor method (122) to confirm the three-factor solution as in the original version (90, 114). Confirmatory factor analyses (CFA) are more common when a hypothesized measurement model should be evaluated. The reason to use an exploratory factor analysis was that the sample size was somewhat limited for CFA, and exploratory factor analysis can be used to confirm a factor structure (155). The extraction of factors in explorative factor analyses could be criticized (156). To reach a
more objective decision, we used the Kaiser criteria with eigenvalues $>1$ to extract the number of factors and then confirmed these using parallel analysis.

Known group validity, an aspect of construct validity, was supported as the MSPSS had the ability to discriminate between women with hirsutism and nursing students. Women with hirsutism scored significantly lower social support compared to nursing students, as was hypothesized according to earlier studies (119,125). Known-group validity is not only a test of construct validity, if a scale successfully discriminates between groups; it also supports sensitivity and responsiveness (49). Related to the endorsement of the items, the low level of missing data and only related to a few of the participants, indicates that the items are easy to understand and relevant for respondents taking the test.

In Studies IV and V we used well established, widely used instruments, which have been validated in many different samples worldwide. When analysing DLQI on item-level it was obvious that the results from the interview study (Study I) could be further verified with the DLQI questionnaire, implicating that DLQI has good content validity in the group of women with hirsutism even if we have not conducted/performe a validation study. DLQI has also been used in other samples and settings of women with hirsutism and has shown to be responsive to clinical changes (83).

The constructors of HADS, Zigmond and Snaith reported good psychometric properties of the initial tests and this has been further validated in other studies (157). The scale has been found to have low misclassification rates (52). The results shown with EQ-5D in the anxiety and depression domain were in concordance with the results when using HADS in Study IV. EQ-5D has been found to be useful in detecting anxiety and depression (158). HADS has been used in other studies including women with hirsutism (80, 82).

SF-36 has been translated, culturally adapted and validated into Swedish by Sullivan, Karlsson and Ware (159). It is one of the most used HRQoL instrument and has also been used in different dermatoses, e.g. acne, psoriasis, atopic dermatitis and hand eczema (160, 161).

Reliability means determining that a scale or measurement yields reproducible and consistent results (49). In Study III reliability tests were performed. Internal consistency was good (Cronbach’s alpha, 0.91-0.95) for all the MSPSS scales, both in the main and reference sample. High alpha values could reflect redundant items. However, there is no clear definition of what a too high alpha value is (162). Streiner and Norman suggest that alpha values should not exceed 0.9, while Nunnally and
Bernstein (122) state that clinical scales should have alpha values of at least 0.9. High alpha values have also been seen in other studies using MSPSS (108, 114, 163). One solution could be to shorten the scale (164). This works well for scales with a large item pool, but not for MSPSS, which does not have so many items, and reducing these should probably have a negative impact on content validity. In addition, although two inter-item correlations were very strong (>0.9), the rest were in the range of 0.42 and 0.87.

The reliability in terms of reproducibility (test-retest) was satisfactory for both items and scales. All except item 5 (“I have a special person who is a real source of comfort for me”) demonstrated good or very good reproducibility. One explanation for this may be related to the Swedish translation and adapting of “significant others” into “an important person in my life close by”. It is possible that this adaption makes it difficult to distinguish items from the subscales Significant others and Friends. However, these tests were conducted on the reference sample with young nursing students and besides that, there was only a moderate correlation between these two subscales. In addition, the rest of the items in the subscale Significant others (items 1, 2 & 10) demonstrated good reproducibility.

SF-36, EQ-5D and HADS have been used in a multicentre European study with patients with heart diseases, where all instruments have been found to be psychometric sound, according validity and reliability(165). As for SF-36, EQ-5D is translated and validated in a Swedish population (57).

**Why measure?**
Measuring HRQoL in clinical research has become more frequent these days. Physicians may not have an accurate perception of the impact a disease has on the patients QoL (69). Physiologic measures provide information to clinicians but are of limited interest to patients as they correlate poorly with well-being and functional capacities (61). However, if measuring, it is important to consider that it might give the patient expectations that the meeting with the physician also should include a supportive dialogue. This could be difficult to have time for in a busy practice.
CONCLUSIONS

- The overall aim was to investigate and describe how women’s body experience, life and health-related quality of life was affected by living with hirsutism. The studies showed that their life was more deeply affected than what has been known previously. Results from the qualitative article in Study I were further verified in the studies including questionnaires.

- The hirsutism was the women’s life-sorrow. They wanted to flee from themselves. This life-sorrow has negative effect on HRQoL and the mean DLQI was 11.8 ± 8.4, indicating a very large effect on patients’ lives.

- In the medical encounter the women mostly felt rejected by the physician and even humiliated. A consequence of that might be that the women avoid seeking healthcare even in very serious cases.

- Higher levels of hair growth were significantly correlated to a lower level of QoL, self-rated health status and anxiety and depression. Anxiety and depression lead to lower levels of vitality and health status and become additional obstacles in life.

- The lowest subscale on SF-36 was vitality (VT) that was even lower than has been found in studies including patients with myasthenia gravis and multiple sclerosis. In spite of that the women work to the same degree as most women in Sweden. Perceived social support could be an explanation for that fact.

- The MSPSS is a psychometrically sound instrument in the setting of nursing students and women with hirsutism.

- DLQI seems to be a clinically useful instrument in women with hirsutism. To present the results both as a total score and on an item level gives a more detailed picture.

- SF-36, EQ-5D and DLQI offer complementary information and EQ-VAS is useful in estimating the perceived health status.
CLINICAL IMPLICATIONS

When we treat patients with chronic diseases, it is my firm belief that it is of great importance to have the courage to stay by the patient’s side even if there is no complete cure to offer. This serves as emotional support. It is also important to explain what results, if any, that can be achieved. Restoration into “normality” is not possible; however there are treatment options, both pharmacological and physical. Information about treatment options, and what could be achieved and what could not be achieved should be given by the physician, this serves as informative support. To offer some kind of medical treatment and physician continuity in healthcare can further improve HRQoL for the patient.

Patients with hirsutism are ashamed of their bodies and themselves and it is an effort to seek medical care, many have symptoms of anxiety and depression. The quality of the meetings, i.e. patient-centred, in the clinical encounter is therefore extra important. A patient-physician style that enhances the patient’s empowerment is crucial as is to have a dialogue and invite the patient to become a partner in the treatment. The physician’s biomedical agenda should be complemented not only by the patient’s agenda, but also by the physician’s reflections about his/her own emotions.
RESEARCH IMPLICATIONS

Further studies on treatment for patients with hirsutism are warranted, e.g. in combination with pharmacological treatment and laser/IPL, for instance longitudinal studies in order to investigate if interventions in early adolescence may influence disease development and HRQoL. Also longitudinal studies in other age groups, including pharmacological and physical treatment to see how that could affect anxiety, depression and HRQoL parameters measured by DLQI, EQ-5D and SF-36.

Research in different settings with women with excessive hair growth, i.e. women who not have attended a dermatological clinic, (for instance by inviting participants by Facebook), also to include a control group of women with other facial dermatosis, is suggested.

Qualitative studies in relation to different age groups in other settings, after interventions are also needed.

Furthermore, to study patient-physician relationships in a bigger sample, different age groups and also from the physician’s perspective is warranted.

Studies that compare DLQI with Skindex in women with hirsutism would be useful.

To confirm the factor structure for MSPSS with confirmatory factor analysis is also warranted. This should be done in a larger sample including more men and older persons. It seems also important to determine the predictive validity in terms of cutoff levels and to evaluate differential item functioning for groups often compared, such as gender, age and ethnicity.
SVENSK SAMMANFATTNING


Det finns några få studier som adresserar hur hirsutism påverkar den hälsorelaterade livskvaliteten. Till exempel har de italienska forskarna Sonino och Fava påvisat högre grad av social oro, ångest, depression och psyketiska symtom hos kvinnor med hirsutism i jämförelse med kvinnor utan hirsutism. Andra forskare har sett att kvinnor med hirsutism känner sig lurade på sin identitet som kvinnor. Hirsutism i förhållande till kroppsuppfattning, stigma och socialt stöd är däremot inte alls studerat. Inte heller hur kvinnorna uppfattar patient-läkarrelationen när de söker för sitt problem.

Det övergripande syftet med avhandlingen har varit att beskriva hur livet påverkas för kvinnor som lider av hirsutism. För detta ändamål har både kvalitativa och kvantitativa metoder använts.


I studie III var syftet att översätta, anpassa och psykometriskt utvärdera ett mätinstrument för subjektivt uppfattat socialt stöd. Detta instrument användes sedan i studie V, för att se om socialt stöd kunde påverka den uppfattade livskvaliteten. Det mätinstrument som valdes och översattes till svenska var the ”Multidimensional Scale of Perceived Social Support” (MSPSS), eftersom det är kort och enkelt samt har goda psykometriska egenskaper. Vidare är det översatt till många språk och använd i många olika sammanhang, både i forsknings- och i kliniska sammanhang. Översättningen genomfördes enligt det rigorösa sätt som rekommenderas av WHO, validerades och anpassades kulturellt för en svensk miljö. I denna studie ingick 127 kvinnor (huvudgruppen), från tre olika centra i Sverige och som diagnosticerats med hirsutism. Referensgruppen bestod av 154 universitetsstuderande som gick andra året på sjukköterskeprogrammet.

En explorativ faktoranalys gav en trefaktor lösning precis som i det engelska originalet och validitet och reliabilitet visade sig vara bra också i den svenska versionen. (Validitet = instrumentet mäter det som det är ämnat att mäta, Reliabilitet = stabilitet, samma resultat fås vid upprepade mätningar).

I studie IV var syftet att beskriva olika aspekter av livskvalitet i mätgruppen (kvinnor med hirsutism) med välkända mätinstrument, både generiska (ej sjukdomsspecifika) och mer specifika. Ett ytterligare syfte var att undersöka korrelationen mellan livskvalitet samt parametrarna ångest, depression, grad av härlighet, BMI och ålder. Det icke sjukdomsspecifika instrumentet EQ-5D, det hudspecifika Dermatology Life Quality Index (DLQI) samt ett screening instrument för ångest och depression, Hospital Anxiety and Depression Scale (HADS), användes. För att skatta grad av härväxt dikotomiserades (= delades upp i två grupper) F-G score. I den ena gruppen hade kvinnor ett F-G-score på mindre eller lika med 14 och i den andra gruppen ett score på 15 och uppåt (Max värde är 36). Högre
nivåer av hårväxt var signifikant korrelerade med lägre grad av livskvalitet, mer ångest och depression. Livskvaliteten för hela gruppen mätt med DLQI var 11.8± 8.4, vilket enligt en klinisk gradering enligt Hongbo är liktydigt med en stor påverkan på livet för patienten. Trots att kvinnor med hirsutism uppradde mer depression och ångest samt hade lägre livskvalitet, så arbetade de i samma utsträckning och hade ungefär samma sociala situation som kvinnor utan hirsutism.

I studie V ville jag därför se om graden av upplevt socialt stöd kunde vara en förklaring till detta. Den nyligen översatta versionen av MSPSS (för socialt stöd) och det generiska instrumentet Short Form 36 (SF-36) användes. I denna studie ingick också en svensk referensgrupp, bestående av 1115 svenska kvinnor i åldern 18-45 år. Alla åtta dimensioner av SF-36 uppradde lägre värden (sämre livskvalitet) hos de hirsuida kvinnorna i jämförelse med kvinnorna i referensgruppen. Det mest påtagliga resultatet var dock den låga grad av vitalitet som kvinnor med hirsutism uppradde. Vitaliteten var inte bara lägre än i referensgruppen, utan också lägre än vad som har påvisats hos patienter med Multipel skleros och Myastenia gravis, mätt med SF-36.

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