PSORIASIS CARE CONSUMPTION
AND CONSEQUENCES OF HAVING
PSORIASIS IN EVERYDAY LIFE

Margaretha Uttjek

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ABSTRACT
Margaretha Uttjek, Department of Social Work, and Department of Public Health and Clinical Medicine Dermatology and Venereology, Umeå University, S-901 87 Umeå, Sweden.

This thesis concerns a research project about psoriasis care and consequences of psoriasis in the county of Västerbotten in Northern Sweden. The overall aim of the thesis is to contribute to improvement of psoriasis care through increased knowledge of the use and accessibility of psoriasis care, and knowledge of impact of psoriasis on patients’ daily lives by describing and interpreting: (i) accessibility and use of psoriasis care, (ii) consequences of having psoriasis in everyday life, and (iii) dilemmas in psoriasis care and visions of future care among professionals, politicians and administrators.

The theoretical framework in the psoriasis project was based on previous research, theories and concepts about priority setting, stigma, coping and quality of life. Parts of the framework were basis of the project plan and other parts were included in order to analyse the findings. Two different methodological approaches were used as complement to each other. The project started with a questionnaire to all known persons with psoriasis in Västerbotten with questions about socio-economic factors, psoriasis symptoms, psoriasis care, and quality of life. These formed the basis for two studies. The first focused on quality of life, and the other on gender differences in psoriasis care. Qualitative research interviews were made with persons with psoriasis, and with administrators, politicians and professionals. The interviews formed the basis for two studies focusing on consequences of psoriasis, and priorities and visions in psoriasis care, respectively. Findings from the studies are reported in four papers.

Accessibility of psoriasis care influenced the use among persons with psoriasis. Use was also influenced by age, income, joint symptoms and quality of life. Men used psoriasis care more often than women. Both genders expected professional care and amelioration, while more women valued polite treatment. Expectations were fulfilled apart from amelioration. Among decision makers, accessibility and issues on organisation and ethics involved priority dilemmas. The persons with psoriasis stated that visibility of both skin psoriasis and joint changes, as well as being stigmatised, was the worst with living with psoriasis. The visibility and stigmatisation were most difficult in younger
ages. Some of those with both rashes and joint changes thus felt stigmatised in a twofold way. In order to deal with these difficulties, commonly used coping strategies were routinisation of both treatment and of adjustment to the stigmatising process, a strategy which could not be found in literature, and acceptance. These strategies developed with age. Those with large disease extent and joint symptoms run the highest risk of impaired health-related quality of life. Most of the interviewed participants, took power over their lives and by using coping strategies created an acceptable personal quality of life for themselves. Still they could not find anything positive with having psoriasis.

In specialised care as well as local health care, special attention should be paid to gender differences and distance to treatment facilities, and handling of possible stigmatisation in patient care. This thesis suggests that the coping theories should be complemented with routinisation as a coping strategy for psoriasis patients. Also, more research on the usefulness of the letter of referral and its consequence on equality and fairness are suggested.

**Key words:** Accessibility, coping, gender, letter of referral, quality of life, routinisation, stigma, visibility.
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Psoriasis care consumption and consequences of having psoriasis in everyday life

This thesis is based on the following articles:


III. Uttjek, M., Nygren, L., Stenberg, B., & Dufåker, M. Marked by visibility of psoriasis in everyday life. Accepted.


All referencing to the articles will follow the enumeration used above.
1. INTRODUCTION

This thesis is about a research project called “The psoriasis project in the county of Västerbotten” that deals with issues concerning psoriasis care and consequences of having psoriasis. The project was undertaken in the county of Västerbotten in Northern Sweden. In this county summers are short, and the large rural areas within it involve long journey times to health care centres. These are important factors to consider when planning for psoriasis care, as are changes in society. In Västerbotten the professional operational responsibility of psoriasis care in the state sector within the county rests with the Dermatology Clinic at the University Hospital in Umeå. During the 1990s discussions were held at the Clinic concerning the means of improving psoriasis care and make it more effective. However, knowledge of both use and accessibility of psoriasis care in the county was insufficient, as was knowledge of the impact of psoriasis on the patients’ daily lives. Questions were raised as to whether living in a rural county characterised by large areas requiring long journey times to centres for treatment constituted special circumstances. Moreover, the Swedish Psoriasis Association (PSA) sought to emphasise at this stage the need for greater knowledge of the social and economic consequences of having the disease. Social consequences included the suffering experienced from living with psoriasis. The total cost of treating the disease has consequences for the patient’s finances, and part of the cost to patients for ointments and the like is not included in public funding. This funding means the patient paying for visits to state-run health care centres and for prescribed medicine for a subsidised fee, the rest being paid by the public purse. During the early stages of the project PSA representatives were contributing with their knowledge and voicing their point of view on the work carried out through the questionnaire.

The psoriasis project formed part of the developments and improvements taking place in psoriasis care in the county of Västerbotten, and the project was initiated by the Dermatology Clinic at the University Hospital in Umeå. Thus the project started with the aim of gathering more knowledge on the issues of the use and accessibility of psoriasis care and on the consequences of having psoriasis. This was done shortly after the publication of the Swedish Parliamentary Priorities Commission’s (SPPC) report titled “Hard choices of the health care” (SOU, 1995). According to the report such hard choices were...
about priorities relating to improved prospects due to advanced technology and knowledge, changes in social provision and limited resources.

As one of the professionals at the Clinic I was asked to be the principal researcher on the issues in the project. At that time I was, and still am, employed by the Dermatology Clinic as a medical social worker. As I was interested in consequences of having psoriasis and wished to contribute to improvements in psoriasis care, I accepted the suggestion.

1.1 Psoriasis

Psoriasis is a chronic disease, and treatment of today can alleviate but not cure the disease (Fredriksson & Pettersson, 1978; Aschcroft et al., 1999; Langley et al., 2005 for a review). The disease is found worldwide, with variations in the prevalence between different ethnic groups, and it may be absent in populations among indigenous people such as aboriginal Australians and Native Americans from South America (Langley et al., 2005). Approximately 2% of Swedish citizens have the disease, and onset may occur at any age (Hellgren, 1967; Swanbeck et al., 1994; Langley et al., 2005). Two peaks of onset are recognised: at 15-20 and 55-60 years respectively (Langley et al., 2005). Psoriasis is considered to be an egalitarian disease, which affects women and men to the same extent (Hellgren, 1967). The whole body including the nails may be affected, and changes to the skin take the form of small spots or larger patches of plaque (Langley et al., 2005). Psoriasis may also affect joints, and the prevalence of joint pain is high among patients with psoriasis, although only a proportion of this is due to factual arthritis (Alenius et al., 2002). The likelihood of contracting psoriasis is through inheriting it, but environmental circumstances such as streptococcus infections, stress and some drugs may trigger the disease (Swanbeck et al., 1994; Swanbeck et al., 1995; Langley et al., 2005). Furthermore, stress associated with psoriasis can influence physical health, as reported by the patients (Fortune et al., 1997). The severity of the disease varies (Langley et al., 2005). A patient with moderate to severe psoriasis needs regular treatment, entailing high costs and possibly implying financial difficulties for the individual concerned (Finlay, 1995). Having psoriasis may influence the individual’s choice of profession, especially one that involves the use of one’s hands. Although psoriasis is not a contagious disease, people with psoriasis have reported difficulties in making social contact and the need to conceal their psoriasis (Jobling, 1976; Langley et al., 2005). Feelings of being stig-
matised which may result in their concealing their psoriasis, avoiding public places and activities, and also avoiding remarks by others on its appearance and any suggestions that it may be due to leprosy or AIDS, are issues which may affect the quality of life for those with psoriasis (Gupta et al., 1990; Weiss et al., 2002). Jobling (1976) has found gender differences in dealing with psoriasis, for example, more men than women have reported irritation or soreness to be the worst aspect of living with psoriasis, while more women than men have stated the need to conceal psoriasis.

1.2 Psoriasis health care

In Sweden the health care is run by the Department of Health. The National Board of Health and Welfare (NBHW) has been commissioned by the government to provide guidelines and instructions for health care in Sweden (SoS, 2005). The country is divided into 21 geographical areas or counties, in each of which local politicians sit on the county council. Psoriasis care in Sweden is mostly state-run, with a number of private dermatology clinics. This thesis looks at psoriasis care in the state sector. In the county of Västerbotten politicians on the county council are responsible for health policy and priority setting as well as for allocating resources (SoS, 2005). The professional operational responsibility of psoriasis care in the state sector rests with the Dermatology Clinic at the University hospital in Umeå. Moderate and severe psoriasis is treated at the Dermatology Clinic while many patients with mild to moderate psoriasis are treated at local health care centres. Because summers in this county are short, UV treatment for psoriasis is an important remedy. UV treatment facilities exist at the three hospitals in the county and at some local health care centres.

A number of citizens in this county live a long way from such facilities and have to travel up to 150 km or more for UV treatment. These distances mean taking time off from work and/or absenting oneself from family activities, and they entail travel and treatment costs.

When a person with psoriasis wishes to visit a dermatologist, she/he has first to see a general practitioner (GP). The GP then decides whether or not that person needs to see a dermatologist. If the decision is yes, the GP sends a letter of referral to the Dermatology Clinic, where the patient is then placed on a list falling under a group ranked in order of priority depending on the severity of her/his disease. Patients with psoriasis may be placed in one of the prior-
ity groups one to three (see section 1.3), with quite few of them being placed in group one.

Telemedicine has been demonstrated to be useful in this county, where teledermatology has resulted in satisfied patients and extended access to professional care (Carle et al., 2001). Patients living far away from the Dermatology Clinic can visit their GP at the local health care centre, where guidance from a dermatologist is available on special request. Thus patients need not travel to the Dermatology Clinic as often as before. As a result, teledermatology in this county saves time and money for patients as well as for the county council, and this means more efficient use of the dermatologists’ working time (Ekholm, 2002).

In addition, telemedicine from an international perspective is considered to be a cost effective complement to conventional dermatological care for outpatients in rural areas involving long journey times (Oakley, 2000; Wootton et al., 2000). Teledermatology can be used with accuracy for the diagnosis of dermatological diseases, and the cooperation of patients with the use of telecommunication has been seen to be positive (Oakley et al., 1997; Aas, 2001).

Other aspects for considerations in psoriasis care is not just the importance of the severity of psoriasis symptoms, but also the extent to which patients evaluate their quality of life (Zug et al., 1995). In-patient care has been shown to improve both skin symptoms and quality of life and to facilitate subsequent out-patient treatment at local health care centres (Kurwa & Finlay 1995). Others have emphasised the consequences of psoriasis on patients’ daily lives and the need for a psychosocial specialist such as a medical social worker in psoriasis care (Strachan & Williams, 1997).

1.3 Health care policy and legislation

Guidelines for psoriasis care are provided by the Swedish Health and Medical Services Act (HMSA), as is the case for the whole Swedish health care system (Sahlin, 1997). Changes in the society combined with limited resources have all contributed to making more difficult the determining of priorities in health care, which in turn has lead to complementation of the HMSA, as suggested by the Swedish Parliamentary Priorities Commission (SPPC) (SOU, 1995).
The SPPC report

The Priorities Commission report titled “Hard Choices in Health Care” was the result of an investigation initiated by the Swedish government (SOU, 1995). The instructions given to the SPPC were to consider the role of health care in the welfare state, a role based on ethical principles for guidance and priorities in health care. The challenge was to achieve a good standard of health care on equal terms for all citizens without the extra resources that had been available during recent decades. Demands on health care had been rising due to biomedical and demographic developments as well as to public expectations. At the same time the limited resources available had not been sufficient to fulfil everyone’s needs and desires (SOU, 1995). The conclusions in the report suggested an overhaul of the HMSA (Sahlin, 1997; SOU, 1995).

Firstly, the portal paragraph of the HMSA should be built on two basic ethical principles: the equality of the individual, with preference given to those patients showing greatest need for medical assistance (SOU, 1995). Also, the formula for defining goals should be complemented with consideration for a person’s quality of life as well as her/his dignity. The SPPC suggested supplements to the law on four points as a way of helping to ensure that priorities be made according to generally accepted policies, and also to ensure the quality of care: (i) every patient should receive a medical opinion of her/his state of health as soon as possible, (ii) a patient facing a life-threatening disease or injury, or something similar perhaps leading to permanent disability or premature death, should receive care without delay, (iii) a patient with an incurable disease or injury should be offered care to enhance their quality of life and to relieve suffering, and (iv) patients in the final phase of life should be offered palliative care in order to promote their chances of dying with dignity (SOU, 1995).

Secondly, the committee recommended the cooperation of public authorities, organizations and individuals in ensuring that these proposed supplements be incorporated (SOU, 1995). Health care services at county level should accordingly cooperate with services in other counties and universities as well in the areas of financial support and the putting into practice of health care research, and the priorities made in health care should be based on this research (SOU, 1995).

The SPPC report formed the basis for the work with another report titled “Priorities in Health Care - Decision and Application”, which was published by the National Board of Health and Welfare (SoS, 1999). The guidelines stated by the NBHW are in accordance with the HMSA, and the NBHW re-
port was meant to form the basis for efforts at national level to support the determining of priorities in health care (SoS, 1999).

**The Swedish Health and Medical Services Act (HMSA)**

Health care shall be readily provided with regard to demographic, geographic, socio-economic and cultural circumstances (Sahlin, 1997). This care shall be provided in cooperation with the patient, and she/he shall be informed about her/his state of health as soon as possible. Priorities shall be made at different levels. Firstly, priorities shall be made by central government, and thereafter health policy priorities are to be made by the county council and local authorities. Lastly, priorities as regards professional operational matters shall be made at clinics and local health care centres by health care professionals in cooperation with the patient, in accordance with democratically determined targets and guidelines made at local level (Sahlin, 1997).

The suggestions from the SPPC were influential on the revised HMSA which was published in 1997 (Sahlin, 1997). It is based on ethical principles such as: (i) the equal worth and rights of all human beings, (ii) solidarity - the resources shall be given to those with greatest need, and (iii) cost and effectiveness, reasonably balanced, and assessed in terms of improved well-being and quality of life as it affects the dignity of the individual (SOU, 1995). Patients with the greatest need of medical assistance and care as a consequence of illness or injury shall be given preference (Sahlin, 1997).

In the revised HMSA four groups of priorities are identified (Sahlin, 1997). Group I: life threatening and acute diseases, diseases which may lead to lasting disability or premature death, severe chronic diseases, palliative care and care in the final phase of life, and the care of those with diminished independence; group II: prevention and rehabilitation; group III: less severe acute and chronic diseases; and lastly group IV: reasons for care other than disease or injury.

The HMSA also sets out the responsibility of the county councils to contribute to the financing, planning and conducting of research as well as their responsibility to cooperate with universities (Sahlin, 1997).

Accordingly, the health care policy and legislation mentioned in this section determine the type of psoriasis care provided in the county of Västerbotten, and these are carried out at the Dermatology Clinic and local health care centres.
2. RESEARCH REVIEW, THEORIES AND CONCEPTS

The purpose of this section is to integrate a research review, theories and concepts regarding priority setting, stigma, coping and quality of life into a theoretical framework for the psoriasis research project. The accessibility and use of psoriasis care in the county of Västerbotten have been based on priorities determined by both decision makers and patients, and influenced by a number of factors such as the severity and location of the disease, the gender of the patient, and the patient’s distance to treatment facilities. The consequences of having psoriasis include stigmatisation, coping with the disease and quality of life. Theories about priority setting are scarce, although research into this has increased in the latest decade, from which theories are now evolving. Examples of these are the development of a model for programme budgeting and marginal analysis (PBMA) as well as a model for employing fairness in priority setting (Daniels & Sabin, 1998; Mitton & Donaldson, 2004). Furthermore, these two models in combination have contributed theory development (Gibson et al., 2006). Theories and concepts of stigma and quality of life are available, as well as research about consequences of psoriasis on quality of life and stigmatisation of persons with psoriasis (Jones et al., 1984; Crocker & Major, 1989; Ginsburg & Link, 1989; Goffman, 1990; Wahl, 1997; Link & Phelan, 2001; Langley et al., 2005). Theories about coping are well known, and research on coping strategies for living with psoriasis is documented and appropriate to this research (Lazarus, 1966, 1969; Lazarus & Folkman, 1984; Wahl et al., 1999; Fortune et al., 2002).

2.1 Priority setting

Health care in Sweden shall be readily provided with regard to demographic, geographic, socio-economic and cultural circumstances (Sahlin, 1997). Furthermore, guidelines for priorities, based on equality, common interest and cost effectiveness, state that a good standard of health care should be assessed in terms of enhanced well-being and quality of life and of maintaining the dignity of the individual (SOU, 1995). Health care provision rests on both financial and actual or geographical accessibility, and is thus a matter of
priority (Blank & Burau, 2004). Political decision makers in the county of Västerbotten face priority issues when allocating limited resources to different geographic areas as well as to different areas of specialisation (Waldau, 2001). Professionals at the Dermatology Clinic and local health care centres face priority issues in their everyday work as regards managing the Clinic’s limited budget, provide various types of treatment and determining when patients should be placed on the waiting list. Persons with psoriasis determine their priorities on deciding whether they should take time off from work or family activities to receive treatment and deciding the order of that cost to them. Also, they determine their priorities in choosing between the various treatments that might be made available, for instance UV treatment or systemic treatment.

Discussions about the priorities of the Swedish state came about in the 1990s as a result of increased demands on health care, technological development and the economic situation. Such discussions had been held before, but they now included the fundamental values and moral principles set out in the agenda such as equality, solidarity, cost effectiveness and the dignity of the patient (SOU, 1995). Technological developments had made it possible to offer patients new types of treatments (SOU, 2001). This together with demographic changes in society has resulted in for instance a higher number of older patients and politicians as well as professionals facing new priorities. A lower level of in-patient treatment and a greater level of out-patient aided by UV treatment facilities and telemedicine have led to more effective health care. Some of the care previously provided in hospital is today provided in the patient’s home. The changes in the place of treatment have increased the demands made on the skills of the professionals working in these districts (SOU, 2001). Increased and more expensive medication, which includes new biological medication such as receptor blockers and TNF-α inhibitors, involves the determining of yet more priorities among both politicians and professionals on how many and which patients might receive these types of medication (Smith et al., 2005). Clinical experience of these types of medication is limited in the field of dermatology, especially as regards their efficacy and long-term toxicity. Therefore guidelines for their use have been developed in order to ensure maximum benefit to patients with psoriasis and to support the safe and effective prescribing of these types of medication (Smith et al., 2005).

Discussions in Sweden about the determining of priorities have reflected a broader discussion at international level on the same subject. The global-
isolation of the struggles as well as the solutions in the area of health policy has contributed to the comparisons undertaken of efforts made by various countries to resolve health care problems in order to identify similarities and differences (Blank & Burau, 2004). One priority of the World Health Organisation (WHO) is to fight against inequalities in health at global level since there are gaps between rich and poor countries as well as inequalities within individual countries (Zöllner, 2002). As of the end of after the Second World War the predominant goal in health care for the rich nations has been the equal right to the accessibility and quality of health care, and these countries have adopted different strategies in the priority setting (Blank & Burau, 2004). Besides Sweden, the principles underlying the determining of priorities have been formalised in a number of countries including Norway, New Zealand, the UK, the US and Canada (SOU, 1995; Abelson et al., 2003). Given that at least some of these countries contain large rural areas similar to those in Sweden, it is possible that they have faced similar issues regarding accessibility of health care.

Since the county of Västerbotten has large rural areas and long journey times between its centres of population, I was interested in the thinking behind the determining of priorities and experiences of priority issues in countries with similar geographic and economic circumstances. In Norway, for instance, priorities have been based on the severity of a disease, not on special considerations due to large rural areas involving long journey times (SOU, 1995). Studies on how the determining of priorities has been evaluated in Norway have been hard to find in literature, as is the case with evaluations made in New Zealand. In the latter, priorities in health care are targeted at wider availability and a more equal sharing of health care resources, and such considerations may be favourable in large rural areas as well as urban areas (SOU, 1995).

In Canada, another country with large rural areas, discussion and deliberation on the determining of priorities among policy makers and the public have formed part and parcel of reaching an informed and consensual view (Abelson et al., 2003). These deliberations have been conducted in face-to-face meetings where policy makers are represented by health care organisations (which provide and run the health services), health-related organisations (e.g. support groups) and well-being organisations (e.g. parent groups and recreational organisations), together with 12-20 people representing the public. Findings from these studies show that deliberation in face-to-face meetings facilitates
consensus building on priority issues, and also show that deliberation does make a difference to the views of participants on priority issues (Abelson et al., 2003).

Other avenues explored by the Canadians in seeking to develop fair procedures in determining priorities included their use of Daniels and Sabin’s (D&S) model of accountability for reasonableness (Daniels & Sabin, 1998; Gibson et al., 2004). This model is based on theories of fairness and justice in discussions on determining priorities, where decisions should be: (i) publicly available, (ii) based on reasons such as facts or arguments on which “fair-minded” people can agree under existing circumstances, (iii) open to revision in the light of fresh points of view or pieces of evidence, and (iv) subject to enforcement in order to ensure the first three conditions are met (Daniels & Sabin, 1998). Findings from Canada show that the D&S model is adequate in helping determine priorities in various institutions (Gibson et al., 2004). The combination of the D&S model of fairness in priority setting with a model for programme budgeting and marginal analysis (PBMA) is shown to improve the procedures in priority setting in Canada and the UK (Daniels & Sabin, 1998; Mitton & Donaldson, 2004; Gibson et al., 2006). The PBMA is an approach for determining priorities which is based on the same core beliefs as apply for economic evaluation but is considered to be more practical and applicable at a number of levels within health organisations (Mitton & Donaldson, 2004). A PBMA process relies upon an advisory panel charged with identifying areas for service growth and resource allocation respectively, including input from decision makers, management boards and the public. The proposed growth in one area is funded by the allocation of resources in another, within a given budget planning cycle (Mitton & Donaldson, 2004). The combined approach of fairness in priority setting and the PBMA model involved discussion groups made up of decision makers, stockholders and members of the public (Gibson et al., 2006).

Thus considerations in Canada regarding the priority setting are about fairness and economical feasibility and involving the public in its deliberations (Mitton & Donaldson, 2004; Gibson et al., 2006). Since this approach is considered to be practical and applicable at various levels within health organisations it might well be appropriate in large rural areas involving long journey times, depending on the more specific guidelines regarding such areas (Mitton & Donaldson, 2004; Gibson et al., 2006).
The guidelines for determining priorities as set out by county council politicians in Västerbotten are coherent with the SPPC report (SOU, 1995). Inspired by Daniels and Sabin’s model for fairness in priority setting, politicians on Västerbotten’s county council have been working since the 1990s on ways of determining priorities and on their implementation in the health care system (Waldau, 2002). The guidelines concern ethical, medical and economic issues, with high priority being given to those who suffer most or those whose lives are threatened, and also to weaker groups with regard to cost effectiveness and the treatment given (Waldau, 2002). Priorities are based on fairness in decision making and the equal right of access to health care, including geographic access, for all citizens (SOU, 1995). However, since decisions in the area of health policy are made by politicians at county council level, the consequences of such decisions may not always be specific and tangible until these decisions have been implemented by health care clinic professionals, as is shown in the NBHW report (SoS, 2005).

### 2.2 Stigma – mark – label

In this section I want to throw some light on the history of the term stigma and the stigmatisation process as presented in research and theories. The stigmatisation of groups and individuals is a custom which has survived through history, although its veneer has changed along with social developments (Goffman, 1990).

Research studies show that persons with psoriasis may have feelings of stigmatisation, and in some studies these feelings relate to low self-esteem (Ginsburg & Link, 1989; Perrott et al., 2000; Richards HL et al., 2001; Vardy et al., 2002; Schmid-Ott et al., 2005; Langley et al., 2005). Feelings of being stigmatised might for example be caused by the anticipation of rejection, being blemished and secretiveness (Ginsburg & Link, 1989). Feelings of stigmatisation and hopelessness may lead to breakdown with treatment, thus aggravating the disease (Ginsburg & Link, 1989).

The custom of stigmatisation is responsible for daily suffering which leads to depression and suicidal ideation among more than 5% of persons with psoriasis (Langley et al., 2005). Feelings of stigmatisation are not significantly related to age at onset, clinical severity or location of the disease (Perrott et al., 2000; Richards et al., 2001; Langley et al., 2005 for a review). Instead, Richards et al. (2001) have found that feelings of stigmatisation are largely related to psychological psoriasis-related distress and psoriasis-related disability. This
Psoriasis-related distress, in addition to feelings of discrimination, is higher among women than men, while men display more severe clinical symptoms (Richards et al., 2001; Schmid-Ott et al., 2005).

Furthermore, Schmid-Ott et al. (2005) state that diminished self-esteem as well as experience of rejection, situational withdrawal, and concealing of skin symptoms are different aspects of feelings of stigmatisation. However, with referral to Crocker (1999), Vardy et al. (2002) consider that while self-esteem may be impaired by stigmatisation it is the immediate social context and its meaning for the stigmatised person which actually determines the consequences stigmatisation may have for the person with psoriasis.

Research conclusions state the importance of offering persons with psoriasis treatment which include strategies for psychological intervention, such as those with focus on stress management and the curbing of avoidance behaviours, in order to increase the psychological adjustment of patients and improve their ability to cope with psoriasis (Richards et al., 2001; Vardy et al., 2002). Moreover, Schmid-Ott et al. (2005) conclude that by carefully screening different aspects of feelings of stigmatisation dermatologists could improve the quality of life for persons with psoriasis.

The term stigma was coined by the Ancient Greeks and referred to a sign which was cut or branded on the victim’s skin (Goffman, 1990). Slaves, criminals and traitors were examples of those categorised and stigmatised under this custom, giving the public and the bearer to understand that she/he was a blemished and polluted person who should be avoided, particularly in public places. Later, in Christian times, stigma also referred to eruptive blossoms on the skin and bodily signs of physical disorders (Goffman, 1990).

In modern times, efforts have been made to define the concept of stigma (Goffman 1990; Jones et al. 1984; Link & Phelan, 2001). Goffman defines three kinds of stigma: (i) physical deformity, (ii) blemishes of individual character based on mental disorders or drug abuse, and (iii) stigmatisation of the individual due to her/his ethnic origin and religion, the effects of which may be passed down the generations and contaminate entire families, both women and men. However, these same sociological features are found as existed in ancient times. A person may possess an attribute which other people then use as a reason to stigmatise this person (Goffman, 1990).

Jones et al. (1984) define a triple perspective of stigma: an observer/a stigmatiser, a stigma and a stigmatised person. The stigmatiser’s activity and role is emphasised. Instead of the term stigma Jones et al. use the term mark, the
person bearing the mark is a markable person, the observer – the one identified as normal – is an observer and also an actor, a marker; and the victim may or may not be stigmatised, that is to say, marked. The roles of marker and marked person can vary in different groups and societies. Both women and men can belong to either group, markers or marked. According to Jones et al. the term mark is less categorical than the term stigma and more flexible in its applicability. A mark may or may not be a social construct (Jones et al, 1984).

Link and Phelan (2001) include discrimination in defining the concept of stigma, and emphasise that for stigmatisation to occur power must be exercised. Thus they shift the focus from the stigmatised individual to those groups and individuals exercising the power. According to Link and Phelan interrelated components in the stigmatising process are: (i) distinguishing and labelling human differences, (ii) associating human differences with negative attributes, (iii) separating us from them, and (iv) discrimination. Human differences are socially selected for the purposes of clear identification, and in order to create social groups oversimplification of these differences is a prerequisite. The term label is preferred to mark, condition or attribute, since the latter terms refer to something pertaining to the stigmatised person, thereby possibly not making clear the fact that labelling a person out for social significance and stigmatisation is the product of social processes. Instead, the term label is something which is affixed. People, who are labelled, set apart, and linked to undesirable characteristics, and who therefore experience discrimination and loss of status, are stigmatised. In the eyes of the stigmatiser a negatively labelled person is placed low down in the status hierarchy in a way not always obvious to the casual observer. Discrimination may be based on the individual, such as refusing that person employment or the opportunity to rent an apartment. Also, discrimination may be structural in nature, such as facilities not adapted for the disabled person and therefore limit that person’s ability to work or to participate in the activities available to others. This conceptualising of stigma leads to consideration of the many outcomes of the stigmatisation process, for instance discrimination and loss of status, and the consequences of these outcomes. Furthermore, the individual’s strategies to cope with negative labelling may have undesired costs, such as working too hard in order not to be called lazy, and in consequence suffering from hypertension (Link & Phelan, 2001).

As is shown in the theories carried out by Goffman (1990) and other symbolic interactionists, a number of psychological theories state that stigmatised
persons suffer from low global self-esteem, but there is, however, empirical research to contradict this statement (Crocker & Major, 1989; Crocker, 1999). Crocker (1999) argues that the consequences of stigma are reliant on the immediate social context and the meaning of that context for the stigmatised person, and not on any internalised, stable distortion of personality. Moreover, those who fall into the stigmatised category may protect their self-concept in various ways (Crocker & Major, 1989). Crocker and Major make a distinction between global self-esteem or self-worth on the one hand, and self-confidence and ethnic or collective self-esteem on the other. Self-confidence is linked to objective criteria and past performance, such as one’s skills or abilities whether in a specific or general domain. Global self-esteem is linked to feelings of personal self-worth, and thus differs from both self-confidence which is linked to social skills and academic ability, and ethnic or collective self-esteem which is linked to the individual’s evaluation of the of the social or ethnic group of which she/he is part. Global self-esteem or self-worth is a generalised feeling of self-acceptance, worthiness, and self-respect, and this is what is protected in various ways in situations associated with stigmatisation. Conceptually, the individual may regard her/his social group as suffering from low self-esteem, and still have feelings of high global self-esteem or personal self-worth. According to Crocker and Major, the controversy regarding the literature on self-esteem and social stigma stems from difficulties in distinguishing between these aspects of the self-concept. Global self-esteem may be protected by: (i) attributing negative feedback to one’s in-group to prejudiced attitudes of others, (ii) making comparisons with the in-group instead of the out-group, and (iii) devaluing the ways in which she/he as an individual or the in-group fares poorly and valuing the ways in which she/he or the in-group excels. These self-protecting strategies may be used in combination and changed from one to the other when the first is discredited or undermined. Crocker and Major (1989) emphasise that not all persons in all stigmatised groups use these self-protective strategies every time they receive negative feedback, but they do consider these use of these strategies to be widespread.

All these theories maintain that the stigmatising process is a social construct. Goffman (1990) provides a historical view and a definition of the concept of stigma. Jones et al. (1984) provide a similar definition of the concept while further emphasising the active role of the stigmatiser. Link and Phelan (2001) throw further light on the concept by stating that for any stigmatisation to occur discrimination and power is exercised. They use the term label, and
shift the focus away from the stigmatised person to the possible source of the labelling. They are thus unequivocally emphasising the fact that the stigmatisation process is a problem resting not with the individual but with society, their conclusion being that it is necessary to change the relationship of power to that of equality. Furthermore, Crocker and Major’s contribution is their understanding that feelings of self-esteem among the stigmatised are not regularly undermined. This is contrary to the findings focused upon in a number of psychological theories and by symbolic interactionists (Crocker & Major, 1989; Crocker, 1999). By combining these theories I want to set out not only the concept of stigma and the history of the term, but also the way in which small changes to the concept shift the focus from the individual to the view that the stigmatising process first and foremost is a problem that rests with society (Crocker & Major, 1989; Crocker, 1999; Link & Phelan, 2001).

2.3 Coping

In stressful situations, for instance when persons with psoriasis are stigmatised for having psoriasis, they may choose from a number of strategies to cope with consequences of having the disease (Ginsburg & Link, 1989; Wahl et al., 1999; Fortune et al., 2002). Coping is part of the emotional process, as are the individual’s motivation, appraisal of the situation, stress and emotions (Lazarus, 1999). This process involves emotions both positive and negative, and the distinction between the two should not be made too precisely. Emotions characterised as positive may involve troubles and threat, which entails the means to cope (Lazarus, 1999). A Nordic study showed that more than half of respondents considered their psoriasis to be exacerbated by stress, and, in addition, one in three stated that onset of their psoriasis occurred during a period of stress (Zachariae et al., 2004).

Stress constitutes the perception of a threat to oneself which bring to mind a possible response to that threat, and coping is the process of providing that response (Lazarus & Folkman, 1984). The choice of coping strategies available may vary among individuals due in part to different personalities, these being in turn the result of both biological inheritance and socialisation processes (Lazarus, 1966). Stress, the pain from physical injury or emotional suffering, involves appraisal of the immediate situation, and a coping strategy is chosen for that situation (Lazarus & Folkman, 1984). Coping as a process is applicable to all stressful encounters and is defined as
...constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. (Lazarus & Folkman, 1984, p. 141).

Whether the individual’s efforts do well or worse, the process of coping includes whatever she/he actually thinks or does in a specific context, not necessarily what she/he usually does or can be expected to do given her/his personality (Lazarus & Folkman, 1984). Thus coping may for example include avoiding, minimising and accepting the stressful situation at hand. Coping is a process of change, taking different forms from time to time and influenced by the relationship between the individual and her/his environment. Appraisal and reappraisal of this relationship is a part of the coping process. Efforts to cope may be directed both outwards to change the environment and inwards to increase her/his understanding and/or to change the meaning of the situation at hand (Lazarus & Folkman, 1984).

Based on Lazarus’ theories Carver et al. (1989) have constructed a COPE scale which has been used in assessing coping strategies among persons with psoriasis (Fortune et al., 2002; Hill & Kennedy, 2002). The COPE scale contains predetermined aspects of coping. These aspects are: (i) problem focused coping: active coping, suppression of competing activities, planning, restraint coping and seeking of instrumental social support, (ii) emotion focused coping: seeking of emotional social support, acceptance, denial, positive reinterpretation and turning to religion, and (iii) coping responses viewed as less useful: focus on and venting of emotions, mental disengagement and behavioural disengagement. Using this COPE scale, results from the study on coping with psoriasis by Fortune et al. (2002) show that the most frequently used coping strategies were positive reinterpretation, acceptance, planning and active coping, and they show that these do not differ between those with severe and mild/moderate psoriasis respectively. Hill and Kennedy (2002) state that maladaptive coping predicts subjective disability. Such maladaptive coping strategies, especially venting emotions and mental disengagement, were strongly related to psychological distress and subjective disability (Hill & Kennedy, 2002).

A number of other studies with checklists for measuring ways of coping have led on from the theories set out by Lazarus and Folkman (1984). However, a number of these checklists are considered to be grounded in too narrow a concept of coping and no consistent explanation can be assigned to coping scale scores (Coyne & Gottlieb, 1996). Instead researchers are encouraged to
consider using broader-based methods for studying ways of coping, including semi-structured interviews, daily diaries and customised checklists tailored to their specific hypotheses and objectives (Coyne & Gottlieb, 1996).

In this thesis I have used the coping theories set out by Lazarus (1969; 1966) and Lazarus and Folkman (1984), without using either the COPE scale or any checklist with predetermined coping strategies in the interview questions. Also, I have been inspired by Chomsky’s (2000) theory of the language and mind, and the applicability of this theory to furthering understanding of the coping process. At some stage, coping includes the language organ with mind and thoughts, as described by Chomsky (2000) - an organ of the body in the sense of what scientists refer to as the visual system or the immune system and a subsystem of a more complex structure, and as in other systems the basic character of the language systems is an expression of the genes.

2.4 Quality of life

Living with a chronic disease such as psoriasis and coping with its consequences may effect one’s quality of life, therefore knowledge about the impact of the disease on patients’ everyday living, including financial burden, is vital in designing suitable health care programmes (Ramsay & Reagan, 1988; Ginsburg & Link, 1989; Finlay & Khan, 1994; Finlay, 1995; Wahl, 1997 for a review; Lundberg et al., 2000; Vardy et al., 2002).

The concept of quality of life has formed part of the study of philosophy throughout the ages (Megone, 1994; Doward & McKenna, 1998). The quality of an individual’s life concerns whether her/his life is getting better or worse, not about the good life, or the bad life (Megone, 1994). Quality of life also relates to the individual’s living conditions, for instance her/his environment and the culture of a given society. These two aspects of quality of life might be termed private and public quality of life, and a person’s private quality of life is influenced by the public one (Megone, 1994). In considering the impact of quality of life in patients with psoriasis and the general issue of how to allocate limited resources to different types of health care, attempts to measure quality of life have been made and various approaches and methods have been used (Doward & McKenna, 1998; Korte et al., 2004 for a review).

A health-related quality of life (HRQoL) approach has its theoretical base in the biological sciences and the model of organic systems, and focuses on disability and daily functioning (Doward & McKenna, 1998). One core definition concerns the individual’s capability to perform daily activities appropriate
to age and primary social role, such as housework, employment or personal care. According to this approach, individuals who are different from what is considered the norm have a reduced HRQoL (Doward & McKenna, 1998). Questionnaires are often used to measure HRQoL (Korte et al., 2004). The questionnaires may be condition-specific such as the Dermatology Life Quality Index (DLQI), disease-specific such as the Psoriasis Disability Index (PDI), generic such as the Short-Form 36 (SF-36) or a combination of these (Finlay & Khan, 1994; Finlay, 1997; Doward & McKenna, 1998; Korte et al., 2004). The HRQoL approach is frequently used in dermatology studies (Korte et al., 2004). The advance of this approach is that it facilitates the assessment of health care outcomes, while one disadvantage is that it is too narrow to reflect a person’s quality of life which amounts to more than just the restricted criteria of measures of health (Megone, 1994; Doward & McKenna, 1998).

A needs-based approach has been developed from theories about the individual’s quality of life to demonstrate her/his dependency on the satisfaction of basic needs such as adequate nutrition, health, mobility, shelter, state education and employment (Doward & McKenna, 1998). Researchers have suggested that individuals are motivated or driven by their needs (Maslow, 1970; Doward & McKenna, 1998). According to this approach a person’s quality of life is achieved by her/his capability to satisfy these basic needs, which may be inbred or learned during socialisation processes (Hörnquist, 1982; Doward & McKenna, 1998). Satisfaction of most human needs results in a high quality of life, and results in a low one when few needs are fulfilled. One tool for measuring quality of life using this approach is the Quality of Life in Depression Scale (QLDS), which has been developed on the basis of interviews with patients and has been tested for reliability (McKenna & Hunt, 1992; Doward & McKenna, 1998). The advantage of this approach is that all aspects of life may be taken into account, but it is criticised among HRQoL researchers for being too wide-ranging in considering all the potential influences on quality of life and thus too impractical (Doward & McKenna, 1998). Moreover, as needs-based instruments are condition-specific, comparisons between patient groups cannot be made, and the same instrument cannot be used with different diagnostic groups (Doward & McKenna, 1998).

The individualistic approach has as its focus the description of quality of life in the individual’s own words (Doward & McKenna, 1998, Joyce et al., 1999). This approach is based on the beliefs of the American philosopher Royce during early twentieth century (Doward & McKenna, 1998). A human being lives
her/his life according to a human life plan. This plan is advanced by qualities such as mobility, the way of one’s heart and intelligence, while other characteristics such as pain, confinement to bed and fear are obstacles to the advancement of that plan. According to the individualistic approach the individual’s quality of life is what she/he says it is (Doward & McKenna, 1998). Advocates of this approach argue that even where the content obtained from using instruments to measure HRQoL is derived from patients, the factors that come to light and the responses to these factors do not represent free choice on the part of the individual (McGee et al., 1991). Instead, the patients have been imposed on them a value system not of their own but one based on results typically presented as deviations and sample means from populations other than the one currently being studied (McGee et al., 1991). Like the needs-based approach, the individualistic approach considers the influences from important circumstances other than health on quality of life. The first instrument developed for measuring quality of life following the individual approach is the Schedule for the Evaluation of Individual Quality of Life (SEIQoL), which is based on judgement analysis derived from social judgement theory (Doward & McKenna, 1998). This instrument, which is used in a semi-structured interview, contains questions on five aspects of the participant’s life considered the most important at that time (O’Boyle & McGee, 1992). The instrument has been further developed for health clinic situations, the SEIQoL-direct weighting (SEIQoL-DW), which is based on weights of patient-nominated life areas (Hickey et al., 1996). The advantage of the individualistic approach is that it lays emphasis on the individual’s own words and stresses the importance of having the patient participate in decision making on her/his treatment (Doward & McKenna, 1998). The major limitation of the individualistic approach is that the instruments developed from the life plan theory have a focus on functioning, despite the underlying theories emphasising the fulfilment of needs. Moreover, this approach is regarded as impractical for clinic situations due to its complexity through the use of qualitative data and due to the need for a trained interviewer (Doward & McKenna, 1998; Moons et al., 2005). Moons et al. (2005) have been addressing this problem of complexity by consulting experts on the issue of quality of life and of the use of qualitative research. In addition, Moons et al (2005) state that it is possible to use the SEIQoL-DW in large samples in order to acquire in-depth information on patients’ quality of life, and also maintain that this represents a paradigm shift in the measurement of the quality of life concept.
Quality of Life in patients with psoriasis has been studied from different perspectives (Doward & McKenna, 1998). Many instruments used in quality of life studies in dermatology use the HRQoL approach, for example, the DLQI for dermatology diseases (Finlay & Khan, 1994; Finlay, 1997; Korte et al., 2004). This instrument measures whether and to what degree the disease has affected the quality of the subject’s life during the past week (Finlay & Khan, 1994). Psoriasis patients have reported a lower HRQoL than people in general, and the greatest differences were on a role emotional scale according to the generic instrument SF-36 (O’Neill & Kelly, 1996; Wahl et al, 2000). A study using the PDI shows that HRQoL has a greater impact on the age group 18 to 45 in relation to appearance as well as occupational and financial difficulties (Gupta & Gupta, 1995). Localisation of the disease in certain body areas such as the hands is associated with impaired HRQoL, especially among women (Gupta et al., 1990; Finlay & Coles, 1995; Touw et al., 2001). In addition, the localisation of the disease on, for example, the head and ano-genital area may affect an individual’s appearance, self-image and sexuality (Gupta et al., 1990). Gender differences regarding the impact of psoriasis on HRQoL based on the PDI and DLQI respectively have been found (Gupta & Gupta, 1995; Zachariae et al., 2000). Men have greater work-related stress than women according to the PDI, while psoriasis has a greater impact on women’s overall HRQoL according to DLQI (Gupta & Gupta, 1995; Zachariae et al., 2000). A Swedish study on HRQoL using the DLQI found no gender differences in total DLQI scores (Lundberg et al., 2000). In making comparisons between social classes, it seems that patients from lower social classes suffer the effects of psoriasis more than do those from higher classes (O’Neill & Kelly, 1996).

A study on HRQoL, using the SAPASI and SF-36, showed that compared with other diseases such as cancer, heart disease, diabetes and depression, psoriasis has similar or greater negative impact on HRQoL (Rapp et al., 1999). Furthermore, the Swedish study on HRQoL, using the DLQI, found that in those patients with psoriasis arthritis perceived HRQoL was lower than was the case in patients with either skin psoriasis or atopic dermatitis (Lundberg et al., 2000).

However, the concept of quality of life is the subject of discussion, and little consensus on a definition of the term is seen to exist (Hendry & McVittie, 2004). The focus on methods of measurement has led to overlooking the wider aspects of quality of life (Hendry & McVittie, 2004).
In this thesis the term quality of life is used, except in the case of paper III where quality of life is termed life quality. I use these terms as synonyms, the reason for this variation being only to follow the recommendations of the journal’s editor. In order to make a distinction between findings on quality of life using quantitative methods, including DLQI (Finlay & Khan, 1994), and qualitative descriptive method, the former are specified as health-related quality of life (HRQoL) and the latter personal quality of life (QoL) respectively.

2.5 Summary

These theories, research review and concepts regarding issues on priority setting, stigma, coping and quality of life are all relevant in the construction of a theoretical framework for the research presented in this thesis. Parts of this framework have involved directing the design of the project, while other parts have been added in order to analyse findings and give them meaning. The different approaches, a HRQoL type as well as a qualitative descriptive type which includes the individual’s own words about her/his quality of life, view quality of life on a wider scale. These studies of quality of life on a wider scale are scarce, as are studies on care consumption from a gender perspective. Gender is the term used most in this thesis, since my main approach is to study the way in which women and men with psoriasis act and receive health care treatment in terms of their status as social beings. Furthermore, studies on coping with psoriasis in everyday life using a qualitative descriptive approach as is the case in this thesis, in addition to studies on priority dilemmas among decision makers with the same approach, are scarce. Thus this thesis serves to complement the research done so far and to contribute to our present knowledge. Through this broader knowledge, it is my intention that the findings in this thesis contribute to improved psoriasis care.
3. AIMS

The overall aim of this thesis is to contribute to improvements in psoriasis care through a broader knowledge of both psoriasis care consumption and consequences of having psoriasis in everyday life in the county of Västerbotten.

3.1 Specific aims

- To describe and interpret the use and accessibility of psoriasis care.
- To describe and interpret consequences of having psoriasis in everyday life for those with the disease.
- To describe and interpret dilemmas and visions of future psoriasis care among professionals, politicians and administrators.
4. SUBJECTS AND METHODS

The methods provide a framework for collecting data on the accessibility and use of psoriasis care and consequences of living with psoriasis. I have chosen quantitative as well as qualitative methods in order to complement each other, an approach similar to that described as situationalist view (Dahlgren et al., 2004). Quantitative methods with predetermined choice of answers were used in order to reach many participants at the same time and to test specific hypotheses on views considered important in improving psoriasis care. In order to acquire a broader knowledge, another important factor in improving psoriasis care, qualitative descriptive methods were used (Sandelowsky, 2000). Themes raised in the interview study were in part influenced by the questions raised from the questionnaire study. Quantitative and qualitative methods were thus used in order to complement each other.

4.1 Hypotheses and subjects for study

In papers I and II hypotheses were formulated and data was collected by means of a questionnaire. Papers III and IV were structured along basic themes and data were collected by means of interviews.

The first hypothesis (paper I) considered the perception that quality of life is influenced by a number of factors in a complex way. In the questionnaire, which included the DLQI (Finlay & Khan, 1994) only some pieces of this complex puzzle could be studied. Age and gender together with social characteristics as marital status, employment and profession were used as independent variables, as were variables connected to the illness such as extent of the psoriasis and accessibility of treatment.

The second hypothesis (paper II) considered the issue that gender differences exist in both expectations and the use of psoriasis care. Since women and men experience different circumstances in life, socially related gender differences were expected.

The main issues in paper III concerned consequences of living with psoriasis on an everyday basis, and the possible differences between women and men in the way they experienced these consequences. The basic questions concerned special situations associated with everyday living with psoriasis.
In paper IV the main issues concerned views on the determining of priorities and the accessibility of state-run psoriasis care, and also concerned the visions of future care as held by politicians, administrators and professionals.

4.2 Participants

Questionnaire

The project started with a questionnaire study in which 1 060 persons with psoriasis participated. The study base constituted all those known by the health care sector to have psoriasis in the county of Västerbotten (papers I-IV). The prevalence of psoriasis is known to be about 2%, therefore out of a population of 250 000 there will be about 5 000 psoriasis patients in the county (Hellgren, 1967). Out of the thirty-six local health care centres, ten submitted their list of patients with psoriasis. Fifteen could not provide patient data, as either registers of diagnoses were lacking or they did not have the time to draw up such a list. The remaining eleven care centres did not reply. Patients who were diagnosed with psoriasis and who visited either one of the ten health care centres from which patient lists were provided, the Clinic of Dermatology in Umeå during 1995–1996, and/or who were members of the Swedish Psoriasis Association (SPA), were included in the database (papers I-IV). Patients who had visited one of the health care centres which did not provide any patient data and those who had not visited the Dermatology clinic or were supporting members of the SPA were lost to the study. The size of this dropout population and the characteristics of these persons are not known. It can only be assumed that most persons in this group probably had a mild form of psoriasis as they were not found in the hospital or SPA registers. The data base contained 1 737 persons. Since 30 of these could not be contacted, a questionnaire (appendix A) was sent by post to 1 707 persons in May 1997 (papers I-II). The response rate was 74% (n=1 255). Out of these 1 255 respondents 195 were excluded as they denied having psoriasis, some of them probably being supporting members of the SPA. Thus the results are based on 1 060 completed questionnaires (papers I-II).

A dropout analysis showed a similar distribution of sex, age and area of residence to that of the respondents (papers I-II). Fifty randomly selected non-respondents were interviewed by telephone. The most common reason for not responding was that the questionnaire was too extensive. Among the fifty, 35% assessed their present condition as very annoying. A valid comparison of
data on the extent of the disease produced from the questionnaire cannot be carried out, but its extent among non-respondents was probably no different to that of the respondents in any obvious way. The conclusion was that the non-participation of these persons has not implied any significant selection bias with respect to sex, age and area of residence (papers I-II).

**Interviews**

The answers from the questionnaire study formed in part a base for the following two interview studies. In the interview studies a qualitative descriptive approach was used (Sandelowsky, 2000).

**Persons with psoriasis**

The participants for the qualitative research interviews were chosen from the data base containing persons with psoriasis (paper III). They were chosen with regard to sex and whether they lived in a rural or urban area in the county. Eighteen interviews were conducted, and the participants were 37 to 74 years old with a mean age of 58. The ambition was to find participants younger than 30 as well, but the four selected for interviews refused to participate, stating that they had nothing to say. Thereafter, additional persons in this age group were selected but they could not be reached (paper III).

**Administrators, politicians and professionals**

In this study, twenty-three key individuals were chosen for qualitative research interviews in view of their position in their respective health care organisations (paper IV). There were as many female key individuals as there were male among administrators and professionals, while among the politicians all were women except for one man (paper IV).

In both interview studies the sample size aimed to give saturation (Strauss & Corbin, 1996) (papers III-IV). Out of eighteen and twenty-three interviews respectively, similar answers and accounts had emerged in a number of these and nothing new in the way of themes had been added, so I decided to do no more interviews. In a letter to all participants in these studies they were asked to participate in an interview. The letter informed them about the project, the voluntary nature of it and the opportunity to say no at anytime. Also, they were informed that they could make corrections to the transcribed interview, which would be sent to them by post. On receiving this information all eighteen in the first study and all twenty-three in the second gave their informed
consent. The interviews were conducted at different times at the three county hospitals, at a youth hostel or else the participant’s workplace during the year 1999-2000. The place for the interview was chosen with a view to minimising the participants’ journey times (papers III-IV).

4.3 Data collection, instruments and procedures

Questionnaire

The questionnaire (appendix A) contained 62 questions on demographic data, economic and social status, symptoms, treatment, cost of treatment, use of psoriasis care, withdrawal from treatment due to either distance or cost, the patients’ expectations of medical care and the ways in which these expectations have been met, perceived HRQoL, and the extent of the disease by showing on a sketched drawing the maximum area of skin affected during the past year and month (papers I-II). In the form of a discussion group members of the PSA contributed with their views on the content of the questionnaire (papers I-II).

There is an authorised Swedish version of DLQI for measuring HRQoL in persons with dermatological diseases (Finlay & Khan, 1994; Lundberg et al., 2000) (papers I-II). HRQoL in papers I-II was measured using a revised version of the DLQI, which included ten questions focusing on sensory symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment. Since some patients may have had more than one skin disease, they were explicitly asked in what way they felt their psoriasis had affected their daily lives during the past week. Also, one question was more specific than provided for in the authorised version in that it asked in what way the disease had influenced the patients’ clothing and choice of clothing. The above constituted the few exceptions to the authorised version of the DLQI (Finlay & Khan, 1994; Lundberg et al., 2000). Wide experience of the use of the DLQI has confirmed the appropriateness of its applicability in clinical settings (Lewis & Finlay, 2004) (papers I-II).

Variables

Variables that fitted the hypothesis were selected from the questionnaire (papers I-II). Age and gender, as well as social indicators relating to the exposure of patients to other persons such as marital status, gainful employment and profession, were independent variables. Also, the extent of the disease, eco-
nomic status, area of residence, distance to UV treatment facilities and withdrawal from treatment were chosen as independent variables (papers I-II).

The extent of the disease was expressed in terms of the presence of joint symptoms, the maximum skin area affected during the past month and year and its location on the head, hands and ano-genital area (marked on a body area sketch by the patient) (papers I-II). The area on the body affected by psoriasis was calculated by a method similar to that used in the Psoriasis Area and Extent Index (PASI) (Fredriksson & Pettersson, 1978; Fleischer et al., 1999). PASI as reported by patients has been shown to be an acceptable method, the thinking being that the affected area is easier for patients to describe than infiltration and erythema (Fleischer et al., 1999) (papers I-II).

All visits made by the patient to her/his local health care centre and to a private or state-run dermatology or rheumatology clinic during 1995 and 1996 were included in the variable labelled care consumption (paper II). Cost of treatment factors, together with the patient’s own total cost over and above the subsidised fee for all patients (as set by the health insurance system) for treating her/his psoriasis were totalled as one variable. Since the patient’s social life is affected by having psoriasis, visits to a medical social worker constituted another variable (Langley et al., 2005) (paper II).

**Interviews**

In each one of the two interview studies a semi structured guide for which questions to ask, based partly on the previous questionnaire study and partly on professional experience, was used (appendix B & C) (papers III-IV). The basic questions contained in each one of these two interview guides provided a framework, and using the qualitative descriptive approach my main focus was on the participant’s own words and what she/he had to say about her/his experiences of these issues (Morgan, 1993; Sandelowsky, 2000) (papers III-IV).

The questions put in the interviews with persons with psoriasis concerned special situations associated with psoriasis (paper III). For example, they were asked to give an account of one situation when having psoriasis had felt particularly hard, another situation when having the disease did not enter their thoughts, and a third situation when they had felt that their psoriasis had a limiting effect. Follow-up questions concerned for instance their views of the quality of their lives, their experience of the visible effects of psoriasis, distance to treatment and cost of treatment, employment, social networks and global self-esteem. Given that special situations in everyday life associated
with psoriasis as well as priority setting in psoriasis care influence the everyday lives of psoriasis patients, a broader awareness of such special situations was considered essential (paper III).

Administrators, politicians and professionals were asked about their views on current psoriasis care regarding accessibility, financing, letter of referral and priorities (paper IV). They were for instance asked what should determine the placing of a patient in a particular priority group: the severity of the disease, the patient’s own perception of the disease or whether the determinant should be something else. They were also asked to outline their visions of future psoriasis care (paper IV).

The interviews were tape-recorded and transcribed verbatim, while irrelevant information such as repetitions was removed, and the participant received her/his copy for corrections (Kvale, 1996) (papers III-IV). Some of the participants submitted their corrected copies by post or e-mail, and changes were made in the transcribed interviews in accordance with the participants’ views (papers III-IV).

4.4 Analyses

**Questionnaire**

*Statistical methods*

In the HRQoL risk analysis the association between determinants and outcome was calculated using logistic regression on the SPSS version 10.0 for Windows (paper I). The questions were coded as in the DLQI, giving scores from 0 to a maximum index sum of 30. The sum index was divided into three groups of similar size corresponding to a “low”, “medium” and “high” index (Finlay & Khan, 1994). Age, income, disease area scores and DLQI scores were divided into categories of similar size in order to optimise the accuracy of comparisons. Distance to UV treatment facilities was categorised in accordance with recommendations from the SPA, based on the latter’s experience of critical distance, that is, how far persons with psoriasis were prepared to go for treatment. Results were given both as bivariate and multivariate analysis results in order to avoid confounding. The dependent variable, HRQoL, was dichotomised in order to highlight the group of cases considered “high” risk (paper I).
The association between clinical and socio-economic factors on the one hand and care consumption on the other was calculated using univariate and multiple regression analysis (paper II). Chi-square analysis was carried out in order to examine the relationship between gender, socio-economic factors and perceived HRQoL respectively, and visits to a medical social worker. Calculations were made on the SPSS version 11.5 for Windows (paper II).

**Interviews**

In both of the interview studies a qualitative descriptive approach was used (Sandelowsky, 2000) (papers III-IV). The coding process was carried out in accordance with qualitative descriptive methodology, since the intention was to represent as closely as possible the participants’ own words and the views they expressed on the various issues (Sandelowsky, 2000). Using open coding I made categories, inspired by grounded theory, but I did not pursue this method further (Dahlgren et al., 2004). The codes as well as the categories were generated from the data produced in the course of the study (Morgan, 1993; Sandelowsky, 2000). Process charts were made with the categories forming the columns and participants the rows, grouped by gender. In these charts I counted the number of categories and searched for patterns which led to the interpretation of the pattern then found one of interest not only to the most frequent but also to the more infrequent categories. Treatment of the data was modified during analysis in order to accommodate new data and insights on these data. Qualitative content analysis was used in the interpretation, which was made with the aim of minimal inference, since the participants’ views on the main issues and their statements on these formed the basis of my material, and the interpretation was to achieve a greater knowledge of their views (Morgan, 1993; Sandelowsky, 2000) (paper III-IV).

One third of the interviews in both interview studies were coded separately by myself and one of the supervisors in order to promote trustworthiness. The categories found were then compared in a meeting between the two of us some time after the first coding. In all these interviews the codes and categories were either similar or quite similar, and therefore the remaining two thirds were coded by myself (paper III-IV).
4.5 Ethics

My basic ethical standpoint was to respect the participants’ integrity throughout the project and to inform them fully of their right not to participate in the study. They were informed about this right and the project as a whole in the first letter which was enclosed with the questionnaire. Also, they were informed about the confidential nature of the project to protect their integrity. The project has been approved by the Research Ethics Committee at the Faculty of Medicine, Umeå University, and the psoriasis register has been approved by the Swedish Data Inspection Board. The basic integrity of the subjects in the study is thus further protected by the endorsement of these authorities.

On the subject of my interviews with persons with psoriasis, I have been aware of my dual role as medical social worker and researcher of this psoriasis project. The participants with psoriasis might have visited me or come across me at the Dermatology Clinic. Whatever the case, they were informed at interview that I worked there. This might have been both an advantage and disadvantage for the purpose of interview. The advantage might have been my not being a stranger, or maybe they felt safe given my familiarity with the disease and its possible consequences. On the other hand they might have felt inhibited, especially if their views on psoriasis care were critical. I informed them at interview about its confidential nature, and I assured them that the information they provided would be used not to their detriment, but for improvements in psoriasis care, and that their views were of great importance to these improvements. In addition, I informed them that these interviews did not form part of my clinical work.

Considerations in conducting the interviews with politicians, administrators and professionals centred on keeping to the descriptive approach as closely as possible by representing the participants’ own words while at the same time protecting their integrity. Although some of the interviewees stated that they stood by their statements, since one of their tasks as decision maker in the workplace is to order priorities, my standpoint was their equal right along with other participants in any research project to have their integrity protected, which I also ensured.

My role as both researcher and medical social worker has mostly been advantageous in my research. My experience of meeting with psoriasis patients and being part of a team in clinical psoriasis care have been important in conducting interviews as well as in analyses work. Moreover, my many years of
experience as a professional social worker has been a strength in establishing a proper relationship with the participants and neither becoming too involved in their personal stories nor assuming anything in those areas of psoriasis care familiar to me (Sandelowsky, 1986).
5. FINDINGS

The worst aspect of living with psoriasis, with no variation between women and men, was the visibility of the disease and, the labelling and stigmatising process as regards both skin psoriasis and joint changes (paper III). Coping with these difficulties, the routinising of both treatment of the disease and adjustment of the stigmatising process, emerged as a new coping strategy not found in previous literature, and this strategy facilitated the everyday lives of both women and men, and resulted in a satisfactory personal QoL (paper III). Moreover, a risk analysis showed that the strongest risk factors for an impaired HRQoL were the extent of psoriasis and joint symptoms among both women and men (paper I). The effects of psoriasis on particular areas of the body such as hands, especially among women, as well as withdrawal from treatment due to distance and financial restraints also influenced HRQoL (paper I). HRQoL influenced in turn the use of psoriasis care (paper II). Age, income and joint symptoms also had a strong influence on care consumption.

Although both women and men wished to visit a dermatologist at the start, more men actually made the visit whereas women to a greater extent visited a GP and applied topical remedies more often (paper II). In accordance with women’s preferences, the aim of decision makers in priority setting has been that the patient visit her/his local health care centre in the first place, where decisions based on order of priority would determine whether or not the patient be given a letter of referral to a dermatologist (paper IV). The existence or non-existence of a letter of referral has been a topic of debated among politicians, and they had differing views on its merit (paper IV). More women than men stated the importance of being treated in a polite manner in psoriasis care, while both women and men appreciated their receiving professional care and amelioration (paper II). Most expectations were fulfilled, except for amelioration which was not, and this was especially emphasised among the men (paper II). There existed a gap between psoriasis care in practice and visions among administrators, politicians and professionals (paper IV). This gap contained priority dilemmas regarding organisation, including the letter of referral, accessibility and ethical practice (paper IV).
5.1 Personal factors and socio-economic characteristics

Both women and men in the study population were somewhat older than the general population (paper II). Age distribution was similar among both sexes, and the distribution between them was quite even, with 48.2% constituting women and 51.8% men (paper I). The majority of the participants had live-in partners, with a similar distribution among women and men. Approximately the same proportion of participants lived in rural areas and urban centres, and two thirds of the participants were no more than 20 km away from UV treatment facilities (paper I).

Employment figures for the study population were similar to those of the county as a whole, of which 69% were employed and 6% unemployed (SCB, 1997) (paper II). Most of those in work had permanent employment, a similar pattern for both women and men, but types of employment varied between the two (paper I). Most women were employed in the service and retail industries, whereby their work brought them into contact with customers more so than was the case for the men. The most common type of employment among men was craft and its related trades (paper I). Distribution of type of employment was similar in terms of both the county as a whole and the country, with the exception of those occupations for which no training is required (paper II).

Women were on a lower income than men (paper I). Among both women and men the mean income in the study population, after standardising for age, was similar to the general population in the county and the country as a whole (SCB, 1997) (paper II).

Thus, the study population did not vary from the general population except in terms of age distribution (paper II). More women than men had professions which brought them into contact with costumers, and they were on a lower income than men (paper I).

5.2 Visibility

Feelings of being labelled and stigmatised by the visibility of psoriasis in different social situations were the most distinctive features among both women and men, and with no variation between genders (paper III). This included visible skin rashes and lesions and scales falling off rashes on to clothing. Moreover, the labelling and stigmatising process included visible changes to joints due to psoriasis arthritis. Coping strategies mentioned in
participants’ accounts cropped up as a category worthy of consideration. The participants adopted various coping strategies such as concealing their psoriasis and avoiding some situations. With time most of them had learned to live with the disease and had adjusted to new situations. They coped with everyday living with psoriasis by accepting having the disease and/or limitation, turning these into a daily routine which determined their personal QoL. The acceptance of the disease as well as routinisation of treatment and adjustment to the stigmatising process developed with age, while the concealing and avoiding behaviours were coping strategies used by all ages. The fact that the participants lived in different geographical areas did not appear to influence their responses (paper III).

**Stigmatisation and visibility**

The most difficult situations in everyday life, when the participants felt labelled and stigmatised by the visibility of their psoriasis, occurred when they were younger and had to expose themselves in various situations (paper III). Other children at school would tease them for having a contagious disease or other such terms. The participants experienced distress and tried to cover their rashes with garments such as long-sleeved shirts and trousers or dark stockings. Dark clothes on the upper body were however avoided owing to the scales from the rashes located on the patient’s head falling on to the sweater or similar garment. Another way of concealing their psoriasis was more frequent house-cleaning in order to remove scales from flooring, chairs and bed. Many participants avoided or tried to avoid situations and activities where they had to expose themselves, for example, going swimming or participating in school sports (paper III). The hands are visible and are used as an organ of communication, and the effects of psoriasis on the hands constituted a risk factor for an impaired HRQoL, especially among women (paper I). Moreover, more women than men worked in places where the hands to a large extent are exposed, such as in the service and retail industries. Signs of psoriasis on other visible parts of the body, for instance the head and ano-genital area, also affected HRQoL, although not as adversely as its appearance on the hands (paper I).

In addition, the period following the onset of psoriasis was stated to be a difficult one (paper III). This involved the dread of living with the disease and its possible consequences on the participants’ daily lives. The thought of living with the disease for the rest of their lives without the ability, either on one’s
own or with medical assistance, to make it disappear in the sense of bringing about a cure, lead to frustration. This was upsetting for several of the participants, and the prospect of living on their own. These fears were stronger among those with onset at a younger age, and were expressed as future visions of having neither a job, a partner, nor a close friend to depend on (paper III).

Some of the participants had both skin psoriasis and joint symptoms which they attributed to their psoriasis (paper III). After living with skin psoriasis for a number of years and then to start displaying joint symptoms drove participants once again into undergoing a period of adjusting and learning to live with a new and difficult situation. If onset of psoriasis on the skin was hard, having joint symptoms was even harder. Joint pain became an increasingly difficult problem; some of the participants experienced pain day and night, at least periodically, and some were restricted in their physical activities. Living with pain became worse than coping with the rashes, and it was sometimes hard to tell what was worst. Feelings of being labelled and stigmatised were present among those whose joint symptoms led to visible changes in the joints. They therefore felt stigmatised on two fronts, namely the visibility of both rashes and changes to the joints (paper III).

**Coping**

After many years of living with psoriasis all the participants had in one way or another adjusted to the disease (paper III). For those who felt stigmatised the adjustment was twofold. They adjusted to the treatment of the disease and to the labelling and stigmatising process as well. This adjustment lead to both acceptance of the disease and the treatment, and also restrictions on activity such as avoidance, and acceptance of these became part of their everyday lives. Most of the participants said that they had learned to live with the disease and had accepted it. They were no longer bothered about what people outside their closest social circle thought about them. People close to them knew that they had psoriasis and accepted them the way they were. After many years some participants had reached a level where acceptance was the greater part of the adjustment, with briefer spells of frustration when the disease was more active. Many participants compared their situation with others’, considering their own lives to be not that bad after all (paper III).

The participants covered lesions and removed scales as best they could, and avoided particular situations where they did not want to expose themselves (paper III). Over half of the group of participants stated that they still,
after many years of living with psoriasis, felt restricted and never smart of appearance in situations where their psoriasis was visible and where people unknown to them were present (paper III).

**Routinisation**

In learning to live with the disease, most of the participants had adjusted to both treatment of the disease and the stigmatising process, by turning the treatment and coping with the stigmatising process into a routine of everyday life (paper III). The treatment as well as concealing the rashes and avoiding certain situations were developed into a routine like washing themselves and brushing their teeth, and this *routinisation* developed with age. Most of the participants stated that they avoided situations where they would worry if their psoriasis was either visible or public knowledge, and some of them aspired to lead a “normal” life like others (paper III).

A few participants described their feelings of shame and considered themselves to be different, whereas a few others no longer felt stigmatised when they grew older and did not mind if they were seen wearing shorts and short-sleeved shirts while at the same time showing evidence of the disease (paper III). However, most of the participants lived their daily lives by trying to conceal the disease and imposing restrictions on themselves to some degree, and at the same time they maintained that they had learned to live with it (paper III).

**Quality of life**

The clearest risk factors for an impaired HRQoL, measured with the DLQI, were the extent to which their psoriasis had affected their body and also symptoms on the joints among both men and women (paper I). Also, a risk indicator among both women and men was the decision not to undergo UV treatment due to distance to treatment facilities. Among men the age range of 40–49 was another risk indicator, whereas for women psoriasis on their hands, the decision not to go for treatment due to cost, and the age range of 50–59 were further risk indicators. Moreover, there was an inconsistent pattern emerging among women and men as regards type of employment. The results were not significant and there were few respondents in each group, but whereas a the pattern for men showed all their types of employment to be associated with a higher HRQoL compared to that of legislators, senior officials and managers, the reverse held true for women (paper I). HRQoL, in turn, was shown to influence care consumption (paper II).
Personal QoL measured with the qualitative descriptive approach, showed the quality of life of each participant from a broader perspective and by representing more closely the participant’s own words (paper III), than that shown using the health-related DLQI (paper I). Findings from the qualitative approach demonstrated that for all the participants psoriasis had some impact on the personal QoL (paper III). They considered their personal QoL in their everyday lives to be satisfactory, despite experiencing some untoward consequences of psoriasis. For instance, they never felt clean; instead they felt they looked unkempt, unclean and/or restricted in their activities, and the scales from their rashes made their clothing and the space around them look untidy. They knew that they had a chronic disease, and that they would not be cured. Having a family, a job and/or close friends, or feeling themselves to be useful and being well, was shown to have an influence on quality of life among most of the participants, and this facilitated their coping, for example, the routinisation, and not thinking about having psoriasis and/or accepting it (paper III).

A few participants stated that psoriasis had brought something fine into their lives (paper III). They had become more mature, humble and caring towards others. But most of the participants could not find anything positive about psoriasis. The disease had not brought anything positive into their lives. They would rather have not had it. Some of the participants described the dread of not finding a partner or obtaining a job. However, those with a partner or with experiences of having a partner said that their partners had accepted them, contrary to their own expectations. They also had jobs, although some had experienced difficulties in the labour market, in that symptoms such as psoriasis on the hands were a restricting factor (paper III).

A few of the participants considered themselves to be well; that is, free from the disease when they did not have any skin or joint symptoms (paper III). Furthermore, there was a trend, although not a distinct pattern, in the way the participants described their reactions to their psoriasis. Some mentioned the fact that they had been prevented from working or participating in various activities, and described the irritation or frustration this was causing. Others told more about their feelings associated with the disease and its consequences, and their concealing of the disease. Both women and men provided these two different descriptions (paper III).
5.3 Psoriasis health care

Increased demands on health care, technical development and the economic situation in Sweden during the 1990s involved priority dilemmas for decision makers (paper IV). These dilemmas reflected a gap between practice and vision. Decision makers stated that the psoriasis care should be accessible, close at hand for patients and offered on an equal basis for all (paper IV). Priorities in health care were a matter not only for decision makers, but also for patients. For instance, the accessibility of psoriasis care influenced patients’ priorities in deciding whether or not to go for treatment (paper I).

Priorities

Priorities for decision makers involved dilemmas, and these were of three kinds: (i) organisation, (ii) accessibility and (iii) ethics (paper IV).

Organisation

Organisational dilemmas were about where the responsibility for determining priorities should rest, issues regarding economy and the function of the letter of referral (paper IV). As regards the dilemma about responsibility, there were opposing views on where within the organisation priorities should be made. Views on where to draw the line between the various levels of responsibility differed between politicians on the one hand, and the rest of the participants on the other. Some in the latter group asked for more specific guidelines on priorities from politicians. In contrast, some of the politicians taking part maintained that priorities should be the responsibility of professionals in reaching agreement on ways of allocating economic resources. Among the professionals there were views on responsibility at different levels within the organisation. Those politicians who allocate resources should take into account the whole picture - the organisation in its entirety, while the specialist should clearly argue for the clinic at which she/he works (paper IV).

Economic dilemmas were seen to be concerned on the one hand with the limitations attached to offering citizens professional health care because of the gap between resources and demand, and on the other with the question of how to allocate resources rather than that of limitations (paper IV). It was viewed as unrealistic to fulfil all demands due to the scarcity of resources. In contrast to this, some viewed the discussions as being about how to allocate and use these resources (paper IV).
Dilemmas regarding the letter of referral rested with its usefulness on the one hand, and problems on the other (paper IV). These problems were of an administrative nature both within the organisation and for the patients. There were three different aspects regarding the need for the letter of referral. First, there were the pros and cons attached to it. There was a need for a letter of referral for the first visit to the dermatologist in order to receive a diagnosis and to arrange treatment. Following this first visit, when the patient knew the nature of her/his own psoriasis, no letter of referral should be needed. Second, requesting a letter of referral was viewed as a device for directing patient visits in the first instance to the local health care centre for the GP there to advise on the patient’s special needs, and thereafter to the Dermatology Clinic for special care. Third, in this view there was no reason for retaining the letter of referral. It was seen as an inconvenient obstacle for patients, an obstacle which contributed to longer waiting periods for visiting the dermatologist. Among politicians the letter of referral was a topic of debate (paper IV).

Accessibility

Dilemmas facing decision makers regarding accessibility were either geographic or financial. Dilemmas about geographic accessibility were concerned with the feasibility of a decentralised psoriasis care, and where to draw the line in how far the public health system might go in improving accessibility (paper IV). Some decision makers stated that they could not see how it would be possible to fulfil every aim of providing good health care and UV treatment facilities at close range for all. One reason was the scarcity of resources. Others considered accessibility to be a consequence of the individual’s choice of residential area. Those who had chosen to live in rural areas could not be assured of good access to health care (paper IV).

The accessibility of psoriasis care influenced patients’ priorities and thus their use of care (paper I). If the distance from the patient’s home to the treatment facilities increased, use of these facilities decreased among both women and men (paper I). When going for treatment both women and men mainly used their own car, although men used the car more often (paper I). Thus, more women than men used public transport during the same period (paper II).

In addition, a consensus existed among decision makers that persons with psoriasis should be offered treatment facilities at local health care centres close to their homes, with regard to the importance of care on equal terms, independent of distance and financial circumstances (paper IV). Good access
would contribute to reducing the time spent by patients on travel and treatment. Many of the participants considered the presence of a dermatologist to be important in improving accessibility. General practitioners and other staff at local health care centres should be offered teaching and guidance by dermatologists. There was also a call for more dermatologists in order to offer the patients more time for treatment of their special needs (paper IV).

The financial implications of accessibility concerned the feasibility or affordability for persons with psoriasis to make use of psoriasis care, the cost to patients of their treatment, and the degree of help they could expect (paper IV). Use of care was also influenced by gender, age, HRQoL, joint symptoms and income (paper I-II). Level of income influenced use of care among both women and men, but financial circumstances had a stronger influence on women’s care consumption (paper I-II). Although both women and men wished to visit a dermatologist in the first place, more men than women actually made such visits while more women visited a GP (paper II). Furthermore, both women and men visited a medical social worker. Joint symptoms and low QoL among both women and men, and low income as well among men, were strongly related to visits to the medical social worker. A few more men used systemic drugs treatment, and both women and men were prescribed topical and UV treatment to the same extent. More women than men administered their own treatment at home during the period of treatment (paper II).

Direct public financing was viewed among decision makers as a means to reduce inequalities. Public financing means that the patient pays for one year’s worth of care and medicine up to affixed amount, after which care and medicine are provided free of charge (paper IV).

Ethics

Ethical dilemmas among decision makers concerned fairness in determining priorities (paper IV). It was difficult to make fair decisions regarding priorities between groups of diseases and between patients as well as between different geographical areas. The severity of psoriasis should determine which priority group the patient be placed in. The need for a developed methodology of assessing how troublesome psoriasis may be for the individual and the use made of treatment was emphasised. Psoriasis and other chronic diseases were compared with more acute diseases, which could be cured by surgery, for instance. The quantity and usefulness of such treatments were
stated to be easier to measure, since they traditionally use quantitative methods more frequently in medicine (paper IV).

In order to promote fairness in ordering priorities, some of those participants whose work did not involve treating patients with psoriasis desired more knowledge about the disease.

5.4 Expectations and visions of a future care

The main expectations on the Dermatology Clinic among both women and men were that they would receive professional care and amelioration, while more women wished to be treated politely (paper II). All expectations except those regarding amelioration were fulfilled for almost half of the group studied, especially in the case of the men. The changes most desired to the county health care system were shorter distance to UV treatment centres, reduction in cost, more information and time with the doctor, and abolition of the letter of referral. Women and men placed similar emphasis on the desire for these changes, with the exception of the desire to have UV treatment closer to hand, which was a priority more for women than men. Furthermore, more women than men desired information about psoriasis (paper II).

The visions of future psoriasis care held by decision makers concerned a continuing decentralisation of UV treatment and the advantages of telemedicine (paper IV). Psoriasis care would thus be more effective, and the aim to provide good access to care, both geographically and financially, would be facilitated. These measures would reduce journey times and cost for the patients, and would render the standard of care more equal and cost effective. The decision makers further maintained that patients should have more responsibility for their own psoriasis care and should to a greater extent take care of the treatment themselves, and that out-patient care should be developed further (paper IV).

Other visions held by decision makers came in the form of suggestions for new directions in the planning and organising of psoriasis care (paper IV). The health care system as a whole was seen as too hierarchical and rigid. Openness was needed regarding who should run the treatment facilities. These facilities would be where persons with psoriasis would go when they know the nature of their disease and their treatment is routine. Those in positions of responsibility, such as politicians, administrators and professionals, would help each other reach agreement on where the responsibility for these treatment facilities would lie (paper IV).
A further vision held by decision makers was that of establishing a forum for professionals, patients, researchers and politicians where party politics would be put aside, to facilitate the means to address ethical issues and priority dilemmas in psoriasis care (paper IV).

Research and information and also a holistic approach were yet more visions held by decision makers about future care (paper IV). The need for information and research from a perspective broader than the traditional medical one was emphasised. This broader view would incorporate more knowledge of how patients live with their disease, taking into considering the factor of improved quality of life, thereby facilitating fair decision making. The decision makers would also be made aware of a connected whole in the lives of patients. They would, for instance, consider consequences of the stigmatising process which patients may be subjected to. This awareness was viewed as important not only in ensuring fairness deciding on priorities but also in planning the design of health care premises and treatment facilities. This suggestion was made by patients and put to politicians, as patients were not always prepared to use these facilities at the same time as the opposite sex (paper IV).

From interviews with patients conducted in another area of this project, as yet unpublished, I have documented that these patients desired a continuing development of UV treatment facilities in rural areas and the abolition of the letter of referral.
6. TRUSTWORTHINESS

Trustworthiness is about persuasion whereby the researcher is judged to have rendered the conduct of her/his research visible and thus auditable (Sandelowsky, 1993). Auditability means leaving a trail of decisions whereby the reader is able to follow and verify this research (Sandelowsky, 1986; Rolfe, 2006). More specifically, auditability is achieved by describing or explaining such factors as: (i) how the researcher became interested in the issues under study, (ii) the purposes of the study, (iii) how the researcher views the study content, (iv) how subjects were incorporated and approached, (v) the effect of the subjects and researcher on each other, (vi) procedures in data collection and analysis, and (vii) the techniques used to conclude applicability of data (Sandelowsky, 1986).

The merit of qualitative research has been an issue of discussion in seeking to define what constitutes a sound, valid, and/or trustworthy qualitative study (Mays & Pope, 2000; Sandelowsky & Barroso, 2002; Rolfe, 2006). Mays and Pope (2000) state that qualitative research can be assessed using concepts of validity and relevance similar to those in quantitative research. Moreover, Ford-Gilboe et al. (1995) emphasise that the basic issue to address in the study of health care is that of producing high quality research which can improve the health and quality of life of patients, something which might involve multiple research methods with the focus on: (i) quality of data, (ii) investigator bias, (iii) quality of the research process, and (iv) the merit of the findings. However, no consensus on quality criteria has been established (Sandelowsky & Barroso, 2002). Instead of seeking a generic framework for assessing qualitative research, researchers should focus on individual judgements of individual studies (Rolfe, 2006).

Trustworthiness in my view is similar to that described by Sandelowsky, Barroso and Rolfe (Sandelowsky, 1986; Sandelowsky & Barroso, 2002; Rolfe, 2006). By leaving a decision trail through the thesis, I allow an appraisal of whether my research practices are visible and thus auditable to the reader (Sandelowsky, 1986).

The researcher’s interest in the subject matter of the study is important for the purposes of auditability (Sandelowsky, 1986). By outlining my starting point in this project, and the reasons why and how it started, as well as outlining my interest in the issues, I have placed this background in view of the reader.
Furthermore, the researcher’s views on the subject of the study are important (Sandelowsky, 1986). Choices of methods as well as theories for interpreting and explaining the findings and also the conclusions drawn from these demonstrate my views on the themes contained in the project. Since I sought to contribute to improvement of psoriasis care in the whole county of Västerbotten I wished to reach a good number of participants at the same time, and I also wanted to incorporate their views on psoriasis care. Therefore quantitative methods were used in the first stage of the project, after which qualitative research interviews were conducted as I desired information in the participants’ own words about their views on the issues covered by the project (papers I-IV). A qualitative descriptive approach was used in the interviews, because in my view participants are experts on their own experiences in life and their views would provide me with important knowledge of use in improving psoriasis care (papers III-IV).

In the questionnaire study data collection was carried out asking predetermined questions, included the DLQI, which were easy to analyse using quantitative methods and therefore easy to use in identifying strength and weakness in the figures, a factor which might facilitate the application of the results in clinical psoriasis care (Doward & McKenna, 1998) (papers I-II). Using the DLQI enables comparisons to be made in the area of other skin diseases in future research, as the DLQI is a broad instrument within the area of dermatology. In this project I might just as easily have used the PDI for measuring the impact of psoriasis on the participant’s life. However, I received answers to the questions, the DLQI is regarded as a valid tool and it was possible to refer to other studies (Lewis & Finlay, 2004). Thus it seems to be an appropriate choice to use this instrument (papers I-II).

Data collection from interviews with persons with psoriasis resulted from the basic questions asked about special situations in their lives (paper III). These questions were in part influenced by the results from the questionnaire, and thus the findings from the interviews gave more information along these themes. Maybe more specific questions in follow-up interviews would have provided even greater knowledge on the issues concerning the impact of psoriasis on their lives and the variation between genders in the use of psoriasis care (paper III). Moreover, follow-up interviews with participants in both interview studies might have thrown further light on the questions raised in such areas as determining priorities (papers III-IV).
The participants in the questionnaire study were all persons with the diagnosis psoriasis and members of the SPA (papers I-II). As a number of SPA members were shown to be supporting members who did not have psoriasis, another approach might have been to advertise for interested participants in the local newspaper and the SPA newsletter. In this way I might have reached individuals who were lost in the studies carried out since not all health care centres could provide data on psoriasis patients, and I would also have avoided contacting those who had no desire to be a part of the study. In addition, I would thus have saved time and money by not spending time on the administration of the register of persons with psoriasis. However, the register formed the subject base not only for this project but also for future psoriasis research, and therefore the time and money spent on this work was worth it. Furthermore, I chose the approach I used in order to recruit subjects, since in my experience a number of people with a chronic disease do not regard themselves as having it when symptoms are absent, a factor which was confirmed by a few in the drop-out analysis. Therefore I might have had a lower number of participants if I had chosen to advertise (papers I-II).

Participants in the interview study with persons with psoriasis, were chosen from the questionnaire study (Paper III). By advertising for participants in this study along the lines of those chosen for the questionnaire study, I might have reached individuals other than those I did have. The same argument for not choosing advertising approach in the questionnaire study applies to the interview study. However, the recruitment of younger persons, adolescents and younger age groups, seemed to require alternative ways, as so few of them answered the questionnaire, and neither of those persons contacted wished to participate in the interview study. Maybe by working more specifically with individuals in the SPA’s section for young persons with psoriasis I would have ended up with a higher number of participants in the younger age groups (paper III).

In the analyses made in the questionnaire study the predetermined answers were given figures in order to make appropriate analyses according to the hypotheses. The analyses were thereby simplified as were the presentation of the data (papers I-II). In the analyses in the interview studies data were made into codes and categories and interpreted before appearing in presentation form, at all times with the purpose of resembling the participants’ own words as closely as possible (papers III-IV). Since we all have different personalities, we can use language in different ways and attach different meanings to words (Chomsky, 2002). It was therefore important to give the respondent the op-
portunity to make corrections to the transcribed interview and for me to make any required changes.

Using first quantitative and thereafter qualitative methods to complement each other, the results from the questionnaire provided material for further areas of research through interview studies, and gave a broader awareness and knowledge of such factors as quality of life seen from a different perspective and of the stigmatising process (Dahlgren et al., 2004). It may also have been appropriate to start with the interviews, and on the basis of these findings then conduct a questionnaire study (Dahlgren et al., 2004). For example, findings from difficulties reported concerning the stigmatising process could prompt questions set in questionnaire form on what improvements in psoriasis care the participants would prefer.

The results produced from this project have contributed to the ongoing decentralisation of UV treatment in Västerbotten. Conclusions from the studies suggest further improvement in psoriasis care. Moreover, the development of the coping theories suggested in this thesis may be applicable to other situations where persons with chronic diseases are stigmatised.

In this way I have described what I have done and why, thereby rendering the research visible, and I have made it possible for the reader to follow my steps (Sandelowsky, 1986). It is now up to the reader to conclude whether my work is auditable.
7. GENERAL DISCUSSION

With the purpose to contribute to improvements in psoriasis care in the county of Västerbotten, a broader knowledge of the accessibility and use of psoriasis care as well as of consequences of psoriasis on patients’ everyday lives was also required. Given that psoriasis care affects these persons’ everyday lives, an improved standard of that care would lead to an improvement in the patients’ psoriasis as well as an improvement of her/his daily life.

7.1 Accessibility and use of psoriasis care

Geographic accessibility of psoriasis care influenced use among both women and men. Distances of thirty to seventy kilometres were critical because the level of use decreased dramatically in this range. Distance matters: it is a matter of both time and money to the patients as well as to the public purse. Good access is called for in the HMSA, and was a desired goal yet a dilemma for politicians, administrators and professionals. A statement made by decision makers which specifies how close to patients UV treatment facilities could be located in view of limited resources would probably be of value to both patients and the Dermatology Clinic in planning psoriasis treatment.

Although both women and men wished to visit a dermatologist in the first place, more men than women actually made such visits, and women placed a higher priority on being close to UV treatment facilities than did men. Perhaps the women appreciated well-established services such as professional psoriasis care close to home in that would reduce the cost of and time spent on treatment. Cost of treatment mattered more among the women, and financial accessibility influenced use, especially among the women, who more than in the case of the men decided to forgo treatment based on financial reasons (Finlay, 1995; Nyman, 1999). Furthermore, women on a low income are more commonly married to men on a similar income (Bihagen, 2000). When time and money are scarce, women may make time with the family and also family finances a priority over going away for treatment for themselves, while not necessarily seeing this as a sacrifice (Nyman, 1999). This variation between women and men as regards use of psoriasis care may be seen to pose a chal-
lenge for decision makers, as may the variation in geographic accessibility, since equal rights to health care is one of the goals set out in the HMSA.

Patients’ priorities may be to do with more than the question of distance, since half the patients with journey times of over 100 km gave reasons other than distance for their withdrawal from treatment. These reasons included feelings of hopelessness, lack of time, work, family, not wanting to be a burden, mild psoriasis and limited opening hours at the UV treatment. Various coping strategies for helping to make adjustments in everyday life and the ability to treat oneself were perhaps further reasons. As regards the layout of the care clinics, the desire, as expressed by patients to politicians, better to preserve their dignity than what is possible today due to the design of treatment facilities, and not to have to be seen by the opposite sex, may be evidence of a further explanation for refraining from treatment. The design of the clinic may be a matter of cost and priorities in allocating resources, since a common line of views among politicians has been to decentralise UV treatment by providing it at local health care centres, with some decision makers believing this would result in increased cost. However, if such decentralisation does result in increased costs, there may be the matter of priorities as figures from this project, not yet published, showed that up to a certain limit the cost of journeying to treatment facilities was reduced instead of increased for both patients and county council. Should investment in new treatment facilities as part of the decentralisation process influence the cost, maybe the decision makers would come together and determine where in the organisation this cost would be levelled, taking into consideration fairness and patients’ expenses. Furthermore, they would determine with whom the responsibility of making priorities regarding the cost of decentralisation should rest.

Maybe the dilemma regarding limited resources and the ways in which to allocate these resources would be solved by employing methods aimed at fairness in economic planning and priority setting such as those employed in Canada and the UK (Gibson et al., 2006). Similar issues on priority setting have arisen in these countries as has been the case in the county of Västerbotten (Gibson et al., 2006). Such methods may also help to realise the visions of future care described in this study, such as continuing development of the use of teledermatology and decentralisation of UV treatment, as well as a yet more fair approach in priority setting. A realisation of these visions is most likely of value for both patients and cost-effectiveness in health care.
The letter of referral was seen to be a topic of debate. The patients requested its abolition, as it was seen to be an annoying obstacle taking up time and entailing increased cost. While a number of the decision makers agreed with the patients, others saw it as a helpful tool in directing patients in the first place to the GP at the local health care centre and thereafter to the dermatologist as regards their special needs. However, the retaining or abolishing of this letter of referral proved a dilemma for the decision makers. Maybe further research would bring about more knowledge on this issue. One question raised in such research might be whether the letter of referral reduces the level of inequality in the use of psoriasis care among women and men as well as among those living far from treatment facilities and those living close by, or, if not, whether the letter of referral is increasing the level of inequality. Other questions might explore whether men’s demands are fulfilled to a greater extent than women’s when requesting a letter of referral. Further questions might explore whether women voice any request for such a letter in order to see a dermatologist, the person they wished to see in the first place, or whether they wish to have more dermatologists at the local health care centres.

7.2 Visibility and stigmatisation

Findings that visibility of the disease along with feelings of being labelled and stigmatised were the worst aspects of living with psoriasis support results from previous studies on skin psoriasis (Stankler, 1981; Ginsburg & Link, 1989; Richards HL et al., 2001; Vardy et al, 2002; Langley et al., 2005 for a review). Having psoriasis on visible areas such as the hands, especially among women, and on the head and ano-genital area influenced HRQoL. That is, visibility of the hands affected ten predetermined areas in life, but we could not gather information on any other areas possibly affected due to the narrow perspective of quality of life given in the DLQI (Finlay & Khan, 1994). Probably such effects, if any, are not negligible, as the discriminative sensitivity of the hand is an important part of a person’s communication system (Moberg, 1958). This may be a matter of greater relevance to women since their work involved them exposing themselves to customers more than was the case with the men. Interviews using, for instance, a qualitative descriptive approach could perhaps highlight this issue.

The worst aspect of visibility was that it related to feelings of being labelled and stigmatised, a finding which confirmed previous studies (Ginsburg & Link, 1989; Vardy et al, 2002). Theories stating that stigmatising is a phe-
nomenon that stems from exercising power and is a social construct, and that persons having psoriasis are not an embodiment of their disease - they are not “psoriatrics” - were confirmed by the findings in this thesis (Link & Phelan, 2001). Although most of the participants were aware of the labelling and discrimination, and had felt stigmatised at least the first time after the onset of their psoriasis, feelings of stigmatisation were not always present in all situations in their everyday lives and their global self-esteem was not regularly impaired, findings which support previous research (Crocker & Major, 1989; Crocker, 1999; Link & Phelan, 2001). Instead, feelings of being labelled and stigmatised occurred in particular situations, mostly when the person with psoriasis was in out-groups, and they were strongest when the person was young and during the first time after onset (Crocker, 1999; Link & Phelan, 2001). The participants with psoriasis had been teased by others, stigmatisers, for having other and contagious diseases. These difficult experiences during their younger years and the time after onset of their psoriasis, regarding visibility, the feeling of being labelled and stigmatised, efforts to conceal their disease and the fear of being rejected, are similar to findings in other studies (Ginsburg & Link, 1989; Fortune et al., 1997; Link & Phelan, 2001; Weiss et al., 2002). The stigmatisation and fear of being rejected is probably a reflection of the practice of both the labelling and stigmatising of others, which has survived through history while altering its appearance, and the stigmatised individual’s understanding of the out-group’s view of her/his unlikeness (Goffman, 1990; Link & Phelan, 2001). Thus the historical concept of stigma has survived, and the stigmatising process involves the exercise of power, in accordance with previous research (Link & Phelan, 2001). Today stigmatisation may not always be obvious to the casual observer, partly because of legislation against discrimination, and partly because the appearance of the stigmatising process has changed, therefore possibly making it harder for the stigmatised person to deal with (Link & Phelan, 2001). The existence of this invisible stigmatisation emphasises the importance of dialogue with each patient about her/his experiences of having psoriasis, without making presumptions that these experiences necessarily are the result of their being stigmatised, and with respect for the patient’s integrity. Such a dialogue may be a step towards altered power relations and hopefully towards fewer feelings of stigmatisation (Link & Phelan, 2001). Appraisal of the personal impact of psoriasis lies in the hands of the patient as do exercise of the power over her/his own life.
The feeling of being labelled and stigmatised on account of the visibility of psoriasis due to joint changes, and thus the stigmatisation of the individual in a twofold way, which is one outcome of this research project, confirms results from previous research on psoriasis and on disability respectively (Crocker & Major, 1989; Langley et al., 2005). Findings about those who had learned to do things in new ways, or changed activities due to joint changes and pain, are findings similar to a previous study by Zachariae et al. (2002).

7.3 Coping

In all their accounts participants described coping with the disease and/or the feeling of being labelled and stigmatised in their everyday lives, although the basic questions were not focused on any specific coping strategy and the word coping was not used in the interviews (Lazarus & Folkman, 1984; Link & Phelan, 2001). For those being stigmatised this may be a process of coping and adjustment, along with the desire to be accepted in a social context such as a family, a group of friends or workmates, and to feel they were of some use (Lazarus, 1969; Lazarus & Folkman, 1984; Wellman, 1999; Baumsteier et al., 2005). As in other studies my findings included coping strategies such as acceptance, avoidance of certain social situations and public places, and the concealing of their disease (Gupta & Gupta, 1995; Fortune et al., 2002). Coping strategies neither varied between genders nor depended on area of residence. For example, both women and men felt labelled and stigmatised by the visibility of their disease and concealed it, and they also felt irritation and frustration. However, there were variations among individuals. This might be explained by variations between personalities due to different types of biological inheritance, a variation in the use of language, and different cultural and social circumstances influencing the choice of strategies (Lazarus, 1969; Lazarus & Folkman, 1984; Chomsky, 2000). The tendency to variation in the participants’ accounts of concealing their psoriasis on one hand and their activities, soreness and irritation on the other may be a reflection of variations in the use of language as well as variation in lifestyles (Chomsky, 2000). This variation in lifestyle may in the past have been more to do with variation between genders, a situation which no longer applies in the same way due to changes in society (Jobling, 1976).

The routinisation of both treatment and adjustment of the stigmatising process in everyday life events associated with psoriasis emerged as a new and commonly used coping strategy, which aided the adaptability of participants
regarding both the treatment of the disease and living with the labelling and stigmatising process. Treating the disease alongside coping with the stigmatising process was turned into a routine. For instance, signs of psoriasis were concealed, and activities in which the disease was made visible were avoided in order not to be labelled and stigmatised by that visibility. The routinisation, which can be regarded both as a behavioural and a cognitive effort, was developed during a process of coping and adjustment, in which the stigmatising process in everyday life events associated with psoriasis was the most stressful encounter (Lazarus & Folkman, 1984). The participants’ choices of coping strategies in order to facilitate their everyday lives, such as avoiding various situations and concealing rashes as well as accepting the disease, and routinising treatment and adjustment to the stigmatising process, might lead to other unwanted outcomes. For example, avoiding social activities might restrict their daily lives, yet exposing themselves in an out-group involved the risk of being stigmatised. It may perhaps have been like a choice between two evils, and they chose the least evil and accepted it since it offered more advantages than the other. Nevertheless, the routinisation of adjustment to both treatment of their psoriasis and adjustment to the stigmatising process may be seen to be the reclaiming of power by the participants, not only over their own bodies but also over their whole life (Hancock, et al., 2000; Link & Phelan, 2001; Williams, 2005). In addition, the routinisation may contribute to protecting the global self-esteem and lessening the effects of the stigmatising process since power relations are thereby altered, at least in the person’s individual circumstances (Crocker & Major, 1989; Link & Phelan, 2001). This would support previous research which found that members of stigmatised groups do not as a matter of course suffer lower self-esteem; clearly the participants in this thesis showed themselves capable of making their own choices as regards what was good and appropriate for them in any given situation during different periods in their lives (Crocker & Major, 1989). One example of a protective strategy they used was to compare themselves with other individuals with psoriasis instead of those in out-groups, to regard their psoriasis as not being that severe after all, and to regard their personal QoL as satisfactory (Crocker & Major, 1989). However, the stigmatising process is a common feature the world over, and in order to change the effects of this process in society as a whole altered power relations in society are probably needed (Crocker & Major, 1989; Link & Phelan, 2001). As long as this goal is not reached, strategies for psychological intervention as suggested by Richards et al. (2001) and
Vardy et al. (2002) may be of use for those patients who desire such treatment. This emphasises the need for a medical social worker in psoriasis health care (Strachan & Williams, 1997).

Reich (2000) has previously assumed, without going into particulars, that routinisation play a role in the coping efforts of people with illness. Findings in this thesis confirmed his assumption, but no further comparisons can be made, since Reich used other methods and in another context. Nothing in literature concerning routinisation as a coping strategy for use in a context similar to that described in this thesis could be found.

Another commonly used coping strategy was the acceptance of the disease after many years of living and becoming familiar with it, and it was similar to findings in another study (Fortune et al., 2002). This acceptance as well as routinisation of treatment and of adjustment to the stigmatising process developed with age, while the concealing and avoiding strategies were used by all ages and in a number of situations in seeking normalisation. Onset of psoriasis at the age of 30 and below was apparently experienced as more difficult than onset at an older age. Those few who were not bothered by being labelled and stigmatised on the account of the visibility of their disease got psoriasis over the age of 40. These findings support similar results from another study that showed that feelings of being like an “outcast” or “social misfit” appeared more common among young people and those up to the age of 45 (Gupta & Gupta, 1995). Knowledge of psoriasis on the part of the public might have been poorer when the participants were young than is the case today, explaining therefore why they were teased then for having a contagious diseases. One weakness in these age findings is the lack of participants at the age of 30 and below. However, being a young person living with psoriasis today is probably not easier than before (Gupta & Gupta, 1995). Knowledge of psoriasis may be somewhat more widespread, but still appearance and ideal images are important, especially during adolescence (Bengs, 2000). Appearance is probably even more important today than when the participants were younger. This may be one explanation for why no one in this age group wished to be interviewed. Maybe they did not want to talk to a stranger about such an issue. The participants’ stories confirmed conclusions made about the difficulties of having psoriasis at a younger age and were similar to results from the study by Gupta and Gupta (1995). Even though a long time had passed since the participants were young, their stories about their youth were of great relevance. Usually people remember special situations, and this required not the search for some com-
mon truth but for an account of the main issues in the participants’ own words. Given the elapsed time since the participants’ adolescence, this may be seen to strengthen the results as well as be viewed as a weakness. The fact that the participants were adults at the time of interview and probably distanced from those special situations by taking a more adult view may strengthen the results, as do the study by Gupta and Gupta (1995). However, the participants may well have forgotten something, which we all tend to do when looking back, and this may be a weakness.

What choice the individual makes and what advantages she/he might perceive in that choice may vary due to personality, the context of the present and the complexity of the stigmatising process (Lazarus, 1969; Crocker, 1999; Link & Phelan, 2001). The various coping strategies chosen by the participants aided their everyday living with psoriasis. However, most of them could see nothing positive in having psoriasis; they would rather not have had the disease. This was contrary to the findings of another study where positive re-interpretation is one of the most frequently used coping strategies (Fortune et al., 2002). The study by Fortune et al. (2002) focused on coping strategies, whereas the main concern of the present thesis has been to find out more about special situations in daily life, without having a predetermined set of coping strategies. Using a qualitative descriptive approach, my main focus was on the participant’s own words and what she/he said about her/his experiences of which special situations arose from living with psoriasis (Morgan, 1993; Sandelowsky, 2000). In a confidence that the participant was the expert in her/his own lived experiences, my intention was to find out what was in those special situations. In the further analysis I used qualitative content analysis, still with the focus on the participant’s own words (Morgan, 1993; Sandelowsky, 2000). This difference in the use of methods may explain the variation in the findings between the study by Fortune et al. (2002) and those in this thesis. Furthermore, participants in this thesis were seen to enjoy a satisfactory quality of life, although they saw nothing positive about having psoriasis, which may be a reflection of an emotion process as described by Lazarus (1999). This process involves an individual’s level of motivation, as well as her/his appraisal, stress, emotion and coping, and may involve both negatively and positively toned emotions (Lazarus, 1999).
7.4 Quality of life

Aided by their own coping strategies the participants ensured they had a satisfactory personal quality of life (QoL), especially when being with family, friends and/or being of some use. Contrary to expectations when younger, they had found partners and jobs as well. However, the health-related quality of life (HRQoL) was much impaired by a number of factors such as extent of the disease, joint symptoms and the decision not to undergo treatment due to distance to travel to treatment facilities. Thus the findings varied between the two methods of finding out how persons with psoriasis evaluate their quality of life. As it is not appropriate to combine these findings since they are results from two different methods, they may therefore complement each other. Impaired disability does not necessarily lead to a consistently lower level of personal QoL. Although the HRQoL is considered too narrow to reflect a person’s quality of life, a HRQoL approach can be appropriate in health care where assessment of health-related outcome may be valuable (Doward & McKenna, 1998). In making such assessments it may be important to consider which instrument to use with regard to the aim of the study. If the focus of a study is to find out the impact on HRQoL of a specific disease, for example psoriasis, a disease specific instrument such as the PDI might be employed. In discussing the issue of priorities a generic instrument for HRQoL might be preferable, and used with caution as different diseases may have different impacts on quality of life (Finlay et al., 1990; Rapp et al., 1999).

However, wider aspects of quality of life have been under consideration (Hendry & McVittie, 2004). Currently methods exist which describe wider aspects of quality of life, for example by conducting interviews using a qualitative descriptive approach. As the concept of quality of life is a theoretical construct and generally not a common topic of conversation among the public, it may be important at each meeting with a patient to evaluate on continuous basis her/his view of a satisfactory quality of life and furthermore to use the data from these evaluated views as complements to wider-ranging studies of HRQoL (Megone, 1994).

7.5 Gender

The most obvious finding regarding gender was that men used psoriasis care, more than did women, while women visited the GP and treated themselves to a greater extent. This is similar to findings in another study on arrange-
ments regarding psoriasis treatment and patients’ completed treatments in Sweden, in which gender differences are found (Osika et al., 2005). Men received a greater degree of UV treatment and were treated more often at the Clinic, while women to a greater degree treated themselves (Osika et al., 2005). In this way the state financed men’s treatment to a greater degree, a factor also born out in a study on total health care consumption in Sweden (Osika et al., 2005; Jonsson et al, 2006). This latter study on health care shows that men in younger and older age groups make greater use of hospital in-care in Sweden than do women, and that women make more use of outpatient care and pharmaceuticals than do men (Jonsson et al, 2006). One explanation for the lower level of use by women may be family finances (see priorities above). More specific details about the use of psoriasis care on the part of women and men respectively would have strengthened the findings in this thesis. It might constitute issues for future research.

The prevalence of psoriasis is equally balanced between sexes since approximately the same number of women and men have the disease (Hellgren, 1967). However, its consequences may vary between them. We found no variations between women and men in perceived HRQoL, but the consequences of psoriasis in other areas such as that of having visible psoriasis symptoms on the hands, for instance, affected women more than men. Other consequences meant variations in the level of use of psoriasis care and the patient’s personal finances (Bihagen, 2000). These findings may support those of Richards et al. (2001), showing that women experience more psoriasis-related distress than do men. Ensuring gender equality in health care provision is an important and difficult task for health authorities (Jonsson et al., 2006). Since care provided on an equal basis for all is one of the goals of the Health and Medical Services Act (HMSA), combining strategies which include guidelines and regulations may be successful in helping to further knowledge about variations between genders in health care and also in helping ensure gender equality in health care (Jonsson et al, 2006).

7.6 Expectations and visions

Patients’ expectations regarding professional care and having more time with the dermatologist as well as having UV treatment facilities closer to hand may be met if the aim as stated by those at decision-making level to further develop telemedicine is realised. With shorter distance to treatment facilities the cost to patients will probably be reduced, also an expressed desire of
theirs (Carle et al., 2001). In addition, the intention of decision makers to achieve a more effective standard of psoriasis care would be fulfilled (Carle et al., 2001; Ekholm, 2002).

Patients considered the abolition of the letter of referral as an aspect of future care which would give them more freedom to decide when and to where to go for treatment. Compared with men, women’s higher expectations regarding having UV treatment facilities close by and receiving more information about treating their disease themselves were in line with what they actually did. It was also similar to the visions held by decision makers. However, these decision makers’ visions included that the men would treat their disease themselves to a greater degree as well. The fact that amelioration, which was a common expectation among both women and men, was not the case for almost half of the group, may be seen as an important issue for decision makers to take into account regarding future care.

In order to fulfil patients’ expectations as well as decision maker’s own visions, new methods of organisation and also cooperation among decision makers in health care is probably needed, a suggestion also put by decision makers. Such methods might be facilitated by using models for fairness and budgeting in priority setting, as has been studied in Canada and the UK (Gibson et al., 2006). In such models both patients and the public might be represented in discussions about priority setting and budgeting (Mitton & Donaldson, 2004; Gibson et al., 2006).

The concept of a holistic view, one which considers the patients’ situation as a whole of living with psoriasis and one suggested by decision makers, has also been emphasised at national level by the Swedish government, which strives towards the holistic view in Swedish health care (SoS, 2004). However, despite a profound investigation, health authorities have not decided on a specific definition. Therefore the definition of the concept of a holistic view is not a distinct one, although it is important to consider in the eyes of those high up in health care (SoS, 2004). One explanation for the lack of consensus about the definition is consideration of the difficulties that might arise in deciding in which cases it is ethical to take this holistic view while respecting the patient’s dignity and integrity. A holistic view may be of advantage where professionals are considering factors other than the patient’s specific symptoms and this can contribute to an increased awareness of the severity of the disease and can facilitate the treatment arranged, aiding the patients’ recovery and providing satisfaction. This especially applies to psoriasis patients, as difficulties in living
every day with this disease may be hard to detect and therefore these patients may be neglected, although not purposely. One disadvantage of a holistic view which is not clearly defined may arise when such a view is necessary neither for treatment nor for arranging type of treatment and the holistic view becomes a means to control the patients’ lives, or only to meet the professional’s individual need to identify the meaning of her/his own work, expressed in their view as a motivation in their work (SoS, 2004). Respecting the patient’s integrity, for instance when a patient chooses to withdraw instead of participate, is of great importance (Hansson, 2006). As in nature, the body has in this way become something to command and control, and patients can often be at a disadvantage (Hancock, 2000; Hansson, 2006). The power over the patient’s life should rest in her/his own hands. Participants in this thesis have demonstrated their power, not only over their bodies (Williams, 2005) but also over their whole lives, by for instance routinising the treatment of psoriasis and also the adjustment to the stigmatising process, and thereby contributing to a satisfactory personal QoL for themselves. Therefore the patients should be important participants in deliberation groups concerned with future psoriasis care.

7.7 Conclusions

In improving psoriasis care in the county of Västerbotten it is important to consider the patients’ distances to treatment facilities. It is a matter of time and cost for both patients and the public health sector. In addition, it is a matter of an equal standard of care for women and those living far from treatment facilities. Further consideration of these groups would require that the use of the letter of referral be evaluated. It is hoped that issues about whether the letter of referral contributes to or reduces inequalities would be answered.

New methods in organisation, planning and in co-operation at decision-making level in health care might reduce time and cost for both patients and the public health care sector and help with efforts to reduce inequalities. Such methods would include the aim to achieve fairness in economic planning and priority setting, such as the methods used in Canada and the UK. In addition, continued development of decentralisation of UV treatment facilities and considerations about who would run these treatment facilities might be included in future care.

The existence of the stigmatisation process emphasises the importance in psoriasis care of continuing dialogue with each patient about her/his experiences of having psoriasis, without making presumptions that every patients are stigmatised, and with respect for the patient’s integrity. A medical social
worker should furthermore be part of the team in dermatology clinics, with regard to psycho-social consequences of having psoriasis.

This thesis suggests that the coping theories should be complemented with routinisation as a coping strategy for psoriasis patients. The routinisation of both treatment of psoriasis and adjustment to the stigmatising process emerged as a new and commonly used coping strategy, which aided the everyday living with psoriasis, and this strategy could not be found in literature.

### 7.8 Further research

Evaluation research of the use of letter of referral, with regard to the aims of equality and cost effectiveness in health care, would probably lead to broader knowledge for future development of psoriasis care.

This thesis also suggests further research into the variation between genders in their use of psoriasis care, especially given the existence of a paradox in the findings. Both women and men wished to visit a dermatologist in the first place, but more men made such visits.

Lastly, this thesis suggests future research on consequences of having psoriasis on body areas such as the hands and the head, which are more exposed to other people, as results in this thesis showed that having the disease on such areas affected HRQoL.
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