Patient and health care delays in malignant melanoma

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Akademisk avhandling

som med vederbörligt tillstånd av Rektor vid Umeå universitet för avläggande av medicine doktorsexamen framläggs till offentligt försvaret i Bergasalen, Norrlands universitetssjukhus (NUS) byggnad 27 - Kvinna-barn-onkologi-huset, onsdagen den 23 maj, kl. 09:00. Avhandlingen kommer att försvaras på svenska.

Fakultetsopponent: professor Carol Tishelman, Institutionen för lärande, informatik, management och etik; Karolinska Institutet, Stockholm, Sverige
Unlike other cancers, malignant melanoma (MM) is generally visible and can be easily and effectively cured if treated in time. Optimal cure of MM requires early detection, diagnosis and treatment which improves prognosis. Patients as well as the health care organization and its professionals contribute to delayed treatment in various ways. **Objectives:** The general aim of this thesis was to explore reasons for delay in care seeking, diagnosis and treatment of MM. The specific objectives to be addressed were: 1) To explore patients’ decision making about seeking care for malignant melanoma; 2) To identify specific patterns in the decision-making process to seek care for suspect MM, as narrated by women and men; 3) To compare self-reported decision making coping styles between men and women in various ages, who live with or without a partner and are diagnosed with various stages of MM in northern Sweden; 4) To describe and compare patients diagnosed with MM, depending on their initial contact with care, and with regard to age, sex, and MM type and thickness, and to explore pathways and time intervals between clinics from the initial contact to diagnosis and treatment. **Methods:** In studies I and II, 21 and 30 patients, respectively, were interviewed about their decision making to seek care for MM. Study II focused on gender patterns in this decision making. The interviews were analysed using Grounded Theory (I) and qualitative content analysis (II). Study III included 270 people with MM who completed a translated questionnaire (MDMQ) about coping styles in decision making. In study IV the pathways and time delay in health care for 71 people with MM were explored. **Results:** In study I, the insights into severity and feelings of fear and existential threat were identified as key motivators for patients to decide to seek care for a suspected melanoma. Study II showed that gender constructions influenced the care-seeking behaviour. Women acknowledged the skin changes and attempted self-care first. They delayed care seeking due to family responsibilities. Men seldom acknowledged the suspicious skin change, but sought care immediately after prompting, and most often complied with relatives’ advice to seek care. Study III showed that men generally scored higher in buck-passing, while women and those living without a partner scored higher in hypervigilance. Participants with nodular melanoma (NM), scored higher in vigilance than those diagnosed as in situ melanoma. No correlation was found between tumour thickness and coping styles. Some differences concerning treatment of MM were found in study IV between people who initially had sought care at primary health care centres (PHC) and those who had sought care at dermatological and specialist clinics (Derm). Thicker tumours as well as NM were more common in the PHC group. Patients within the PHC group also had to wait longer for the registered results of histopathological assessments. Time delay of diagnosis and treatment of MM is still common, and crucial to decrease. Future interventions should include gender aspects to influence people to seek care earlier. In health care, time delay could be decreased by facilitating access for patients with suspected skin melanomas, but also by reducing unnecessary referrals. Moreover, organizational changes whereby general practitioners and primary health care nurses are supported in using new technology for faster diagnoses and management of MM in collaboration with specialist clinics should be considered. Lastly, more efficient transfer and registration of laboratory results and referrals could decrease delay and improve patient safety. **Keywords** Care seeking, delay, diagnosis, decision making, gender, malignant melanoma, nursing, organization, pathways, severity
Patient and health care delays in malignant melanoma

Senada Hajdarević
Health is not bought
With a chemist’s pills
Nor saved
by the surgeon’s knife.
Health is not only
the absence of ills,
But the fight
for the fullness of life.

From *Are we aware*
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Abstract

Patient and health care delays in malignant melanoma

Background: Unlike other cancers, malignant melanoma (MM) is generally visible and can be easily and effectively cured if treated in time. Optimal cure of MM requires early detection, diagnosis, and treatment, which improves prognosis. However, patients as well as the health care organization and its professionals contribute to delayed treatment in various ways.

Aims and objectives: The general aim of this PhD thesis was to explore reasons for delay in care seeking, diagnosis, and treatment of malignant melanoma. The specific objectives to be addressed were

- To explore patients’ decision making about seeking care for malignant melanoma
- To identify specific patterns in the decision-making process to seek care for suspect melanoma, as narrated by women and men
- To compare self-reported decision making coping styles between men and women in various ages, who live with or without a partner and are diagnosed with various stages of malignant melanoma in northern Sweden.
- To describe and compare patients diagnosed with MM, depending on their initial contact with care, and with regard to age, sex, and MM type and thickness, and to explore pathways and time intervals between clinics from the initial contact to diagnosis and treatment.

Methods: In studies I and II, 21 and 30 patients, respectively, were interviewed about their decision making to seek care for MM. Study II focused on gender patterns in this decision making. The interviews were analysed using Grounded Theory (I) and qualitative content analysis (II). Study III included 270 people with MM who completed a translated questionnaire (Melbourne Decision Making Questionnaire) about coping styles in decision making. In study IV the pathways and time delay in health care for 71 people with MM were explored. Studies I and II were qualitative, whereas studies III and IV were quantitative.

Results: In study I, the insights into severity and feelings of fear and existential threat were identified as key motivators for patients to decide to seek care for a suspected melanoma. Results in study II showed that gender constructions influenced the care-seeking behaviour. Women acknowledged the skin changes and attempted self-care first. They delayed care seeking due to family responsibilities. Men seldom acknowledged the suspicious skin change, but sought care immediately after prompting, and most often complied with relatives’ advice to seek care. Study III showed that men generally scored higher in buck-passing, while women and those living without a partner scored higher in hypervigilance. Participants with nodular...
melanoma (NM), a rapid-growing form of MM, scored higher in vigilance than those diagnosed as in situ melanoma. No correlation was found between tumour thickness and coping styles. Some differences concerning treatment of MM were found in study IV between people who initially had sought care at primary health care centres (PHC) and those who had sought care at dermatological and specialist clinics (Derm). Thicker tumours as well as NM were more common in the PHC group. A larger proportion of patients from PHCs were primarily excided within the primary health care; however, almost all of them were later referred to surgical clinics for wide excision. Patients within the PHC group also had to wait longer for the registered results of histopathological assessments. In general, women waited a shorter time for primary excision, and older people waited longer for wide excision.

Conclusions: Time delay of diagnosis and treatment of MM is still common, and crucial to decrease. Future interventions should include gender aspects to influence people to seek care earlier. In health care, time delay could be decreased by facilitating access for patients with suspected skin melanomas, but also by reducing unnecessary referrals. Moreover, organizational changes whereby general practitioners and primary health care nurses are supported in using new technology for faster diagnoses and management of MM in collaboration with specialist clinics should be considered. Easy access and frequently used guidelines for MM could further decrease delay. Lastly, more efficient transfer and registration of laboratory results and referrals could decrease delay and improve patient safety.

Key words: Care seeking, delay, diagnosis, decision making, gender, malignant melanoma, nursing, organization, pathways, severity
# Abbreviations and explanations

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<tr>
<th>Abbreviation</th>
<th>Explanation</th>
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<tr>
<td>ALM</td>
<td>Acral lentiginous melanoma</td>
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<tr>
<td>Breslow</td>
<td>Scale measuring melanoma thickness</td>
</tr>
<tr>
<td>Clarke</td>
<td>Scale measuring level of invasion in the skin</td>
</tr>
<tr>
<td>CMM</td>
<td>Cutaneous malignant melanoma</td>
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<tr>
<td>CTM</td>
<td>Conflict theory model</td>
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<tr>
<td>GP</td>
<td>General practitioner</td>
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<tr>
<td>HBM</td>
<td>Health belief model</td>
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<tr>
<td>In situ</td>
<td>Malignant melanoma in a non-invasive stage</td>
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<tr>
<td>LMM</td>
<td>Lentigo maligna melanoma</td>
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<tr>
<td>MDMQ</td>
<td>Melbourne Decision Making Questionnaire</td>
</tr>
<tr>
<td>MM</td>
<td>Malignant melanoma</td>
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<tr>
<td>NM</td>
<td>Nodular melanoma</td>
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<tr>
<td>NUS</td>
<td>Norrlands universitetssjukhus</td>
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<tr>
<td>OC</td>
<td>Onkologiskt centrum</td>
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<tr>
<td>PHC</td>
<td>Primary health care centre</td>
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<tr>
<td>P-value</td>
<td>Probability value</td>
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<tr>
<td>SD</td>
<td>Standard deviation</td>
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<tr>
<td>SSM</td>
<td>Superficial spreading melanoma</td>
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<tr>
<td>UV</td>
<td>Ultraviolet</td>
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Original papers

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals, I–IV:


Printed papers have been reprinted with the kind permission of the respective publishers.
Patient- och vårdrelaterad fördröjning av diagnos vid malignt melanom

Bakgrund: Malignt melanom (MM) är till skillnad från andra cancerformer ofta synlig och kan enkelt och kostnadseffektivt botas om det behandlas i tid. En optimal prognos av MM förutsätter tidig upptäckt, diagnos och behandling. Patienter, samt hälso- och sjukvården, dess organisation och dess personal kan på olika sätt bidra till fördröjning av behandlingen av MM.

Syfte: Det övergripande syftet med denna avhandling var att undersöka orsaker till fördröjning att söka vård, diagnosticaera och behandla malignt melanom. Specifika delsyften var:

- Att utforska patienternas beslutsfattande process att söka vård för MM
- Att identifiera specifika mönster i beslutsfattande-processen att söka vård för misstänkt MM utifrån kvinnors och mäns egna berättelser
- Att jämföra självrapporterade coping-stilar i den beslutsfattande processen mellan män och kvinnor i olika åldrar, boende med eller utan partner, och diagnosticerade med MM i olika stader från norra Sverige
- Att beskriva och jämföra patienter med MM utifrån deras primära vårdkontakt samt utifrån ålder, kön, MM-typ och tjocklek. Ytterligare att utforska vård- och remissvägar samt tidsintervaller mellan olika kliniker från första kontakt till diagnos och behandling.

Metod: I studie I och II, intervjuades 21 respektive 30 patienter om den beslutsfattande processen att söka vård för MM. Genuskonstruktioner i relation till den beslutsfattande processen var i fokus i studie II. Intervjuerna analyserades med hjälp av Grounded Theory (I) och kvalitativ innehållsanalys (II). I studie III inkluderades 270 patienter med MM som besvarade ett instrument (MDMQ) avseende coping-stilar i beslutsfattande processen. I studie IV undersöktes övergångar mellan olika kliniker och remissvägar för 71 patienter med MM samt eventuell tidsfördröjning inom hälso- och sjukvården.


**Slutsatser:** Tidsfördröjning av diagnos och behandling av MM är fortfarande vanlig och därför viktig att minska. Framtida interventioner för att påverka människor att söka vård tidigare bör inkludera genusaspekter. Inom hälso- och sjukvården kan tidsfördröjning minskas genom förbättrad tillgänglighet för patienter med misstänkta hudmelanom, men också genom minskning av onödiga remittering. En förändrad organisation där sjuksköterskor och primärvårdsläkare i samarbete med specialistkliniker stöttas att använda ny teknologi för snabbare diagnosticering och omhändertagande av MM bör övervägas. Ökad kännedom bland hälso- och sjukvårdspersonal om riktlinjer för MM-vård kan vidare minska fördröjning. Till sist, mer effektiva och förbättrade arbetssätt kring registrering och överföring av laboratoriska svar och remisser skulle kunna minska fördröjning och därmed öka patientsäkerheten.

** Nyckelord:** Allvarlighetsgrad, att söka vård, beslutsfattande, diagnos, fördröjning, genus, malignt melanom, omvårdnad, organisation, remissvägar
Summary in Bosnian – Rezume na bosanskom jeziku

Kašnjenje u dijagnozi i tretmanu malignog melanoma uzrokovano od strane pacijenata i zdravstva

Pozadina: Maligni melanom (MM) je za razliku od drugih oblika raka često na vidljivim mjestima i može se lako i effikasno izliječiti ako se primjeti i diagnostikuje na vrijeme. Optimalan tretman MM-a zahtijeva rano otkrivanje, dijagnostiku i liječenje što dalje utiče na prognozu. Pacijenti kao i zdravstvo tj. organizacija i osoblje doprinose na žalost na različit način kašnjenju u diagnosti i liječenju MM.

Namjena: Cilj ovog doktorskog rada je bio da istraži i pojasi pre svega uzroke kašnjenja u traženju zdravstvene pomoći kao i kašnjenju dijagnoze i liječenja malignog melanoma. Specifični ciljevi koji su usmjeravali studije su bili:

- istražiti i objasniti šta utiče na ljude i kako se oni odlučuju da traže zdravstvenu pomoć za tretman MM
- identifikovati specifične načine u procesu donošenja odluka o traženju zdravstvene pomoći pri sumnji na MM, bazirano na njihovim pričama
- uporediti lično raportiranu upotrebu raznih coping- stilova (suočavanje, preživljavanje) u toku donošenja odluke o traženju zdravstvene pomoći pri sumnji na MM među ženama i muškarcima iz sjeverne Švedske obolelih od MM u različitim stadijima i različite starosti i na osnovi da li žive s partnerom ili bez njega
- opisati i uporediti bolesnike sa MM na osnovi njihovog primarnog kontakta sa zdravstvom kao i starosti, polu a takođe i tipu i debljini kožnog melanoma. Dalje da istražimo zdravstvenu njegu i proces sa uputnicama kao i vremenske intervalle između različitih specijalističkih klinika od prvog kontakta sa zdravstvom do dijagnoze i liječenja.

Metoda: Intervju o procesu donošenja odluka u toku donošenja odluke za tretman MM sa 21 respektive 30 bolesnika je izvršen u studiji I i II. Studija II je fokusirala na specifične razlike u ženskim i muškim načinima donošenja odluka. Razgovori su analizirani pomoću Grounded Theory-metode (I) i kvalitativne sadržajne analize (Qualitative content analysis) (II). 270 osoba sa dijagnostikovanim MM je bilo uključeno u studiju III gdje je su oni ispunili upitnik (MDMQ), o upotrebi stilova suočavanja - preživljavanja u procesu odlučivanja. U IV studiji istraženi su prijelazi i uputnice za 71 pacijenta sa MM između različitih klinika kao i eventualno zakašnjenje dijagnoze i tretmana od strane zdravstva.

Rezultati: U studiji I, uvid u opasnost od bolesti i strah, kao i egzistencijalna ugroženost zbog stanja bića su pronađeni kao glavni uzroci za donošenje
odluke o traženju zdravstvene pomoći pri sumnji o malignom melanomu. Rezultati iz studije II su pokazali da socijalne konstrukcije o tipičnim razlikama između žena i muškaraca utječu na to kako ljudi traže zdravstvenu pomoć. Žene često same otkrivaju melanom i pokušavaju u početku same primijeniti mjere lječenja. One ponekad i odugovlače sa traženjem pomoći zbog porodičnih obaveza. Muškarci rijetko sami otkrivaju melanom ali slušaju savjete najbižih o potrebi zdravstvenog pregleda i traže zdravstvenu pomoć odmah nakon toga. Rezultati iz studije III su pokazali da muškarci uopšteno vrjednuju više na skali buck-passing (izbjegavanje), dok žene i oni koji su živjeli bez partnera vrjednuju više na skali hypervigilance (prekomjerna budnost). Pacijenti sa dijagnozom nodularni melanom (NM), brzorastući oblik MM, vrjednuju više na skali vigilance (budnost) od onih sa dijagnozom MM in situ, tj. vrlo rani oblik MM. Nikakve korelacije između debljine melanoma i stilova suočavanja-preživljavanja nisu pronađene. Neke razlike u vrstama MM i organizaciji zdravstvenog tretmanu, zavisno gdje su pacijenti prvo tražili pomoć, su nađene u studiji IV. Među pacijentima koji su u primarno tražili pomoć u zdravstvenom centru deblji tumori su bili uobičajeni u poređenju sa onima koji su tražili tretman na kožnim i drugim specijalističkim klinikama. Među tim pacijentima je takođe i primarna ekscizija uglavnom bila izvršena u zdravstvenom centru, i gotovo svi pacijenti su kasnije upućeni na hiruršku kliniku radi potrebe šire ekscizije. Pacijenti iz zdravstvenog centra su čekali duže na registraciju rezultata sa patološkog istraživanja nego pacijenti sa specijalističkih klinika. Žene su uglavnom čekale kraće vrijeme na primarnu eksciziju dok su starije osobe morale čekati duže vrijeme za širu eksciziju.

Zaključak: Kašnjenje u dijagnozi i liječenju malignog melanoma je još uvijek uobičajeno i zato važno da se smanji izbjegne. Intervencije u budućnosti sa ciljem da utiču na ljude da ranije traže zdravstveni tretman treba da sadrže gender- aspekte (socijalno-drustvene konstrukcije o tipičnim razlikama između žena i muškaraca). Zakašnjenje dijagnoze i tretmana se može smanjiti sa poboljšanom pristupačnosti u zdravstvu za bolesnike sa sumnjom na kožni melanoma, kao i smanjenjem broja nepotrebnih i pogrešnih uputa. Promjenu strukture u organizaciji gdje medicinske sestre i lekari primarne zdravstvene zaštite, uz podršku i saradnju sa specijalističkim klinikama, mogu koristiti nove tehnologije za bržu dijagnostiku i liječenje melanoma treba uzeti u obzir. Isto tako povećana svijest i informiranost zdravstvenih radnika o smjernicama za liječenje MM može smanjiti zakašnjenje. Pored toga efektivniji i bolji način rada oko registracije i pošiljki laboratorijskih rezultata i uputa može smanjiti kašnjenje tretmana i povećati sigurnost pacijenata.

Ključne riječi: Dijagnoza, donošenje odluka, maligni melanom, organizacija, pol, putevi u zdravstvu, traženje zdravstvene pomoći, zakašnjenje, zdravstvena njega
**Introduction**

In my work as a primary health care nurse, I often have felt insecure and frustrated over the management of patients seeking care for suspicious skin marks. Nurses in care planning among people seeking care are asked to prioritize among them based on the severity of their state, the promptness of the situation and the level of professional competence needed. Most patients with skin marks have been found to have non-malignant marks; as such, these patients frequently get a low prioritization. On the other hand, patients are influenced by media and health education messages to act quickly, themselves, if they suspect malignant melanoma (MM), and to seek care immediately. Nurses, particularly those working at primary health care centres, in their daily work often have the opportunity to prioritize and identify people with diseases, since there is limited availability to get a doctor's assessment and the resources must be used in the optimal way. All patients have the right to express their worries and suspicions about melanoma when they seek care, but usually far from all of those who are suspicious have malignant melanoma. Nevertheless, their concern must be listened to thoroughly and never dismissed as unnecessary, even if it is not about malignant melanoma. An obliging reception of patients is important to increase reliance on health care professionals’ competences and advice. If all worried patients were taken seriously, the opportunity to decrease delay of diagnosis in malignant melanoma would improve. Many people express that they avoid seeking care because they do not want to bother the health care service unnecessarily.

From my view, the accessibility of primary health care is insufficient and does not conform to the needs of all groups of people in society, for example, elderly people and those who don't use the Internet. Therefore, I consider that it is possible to improve patient reception and also to increase awareness about reasons for delay among health care professionals.
Background

Malignant melanoma

The first case of MM was mentioned in 1787 in England by John Hunter, but it was first described as a disease in 1804 by a French physician, René Laennec. Skin cancer is one of the cancers that has most increased in prevalence in Sweden and the whole world during the past decade (Curado et al., 2007; Garbe & Blum, 2001). According to the Board of National Health and Welfare of Sweden (2011a), 7842 new cases of skin cancer were found during 2010 in Sweden, and of them, 2817 (36%) were diagnosed as MM. The gender distribution among those cases was 52% men and 48% women (National Board of Health and Welfare, 2011a).

There are different forms of skin cancer, but the most common of them are basal cell carcinoma, squamous cell carcinoma, and malignant melanoma. Both basal cell and squamous cell carcinoma develop from the keratinocytes, cells in the epidermis, while MM develops from melanocytes, the cells that build the dark pigment melanin in the skin. Melanomas can also grow in the eye and the meninges and on various mucosal surfaces, and can also deviate from the usually dark pigmentation, being amelanotic (Garbe et al., 2010). In this thesis the term melanoma is used to mean the skin melanoma, or cutaneous malignant melanoma (CMM). Basal cell carcinomas do not spread metastases. Squamous cell carcinoma may spread, but do so less often and mostly to the lymph. Malignant skin melanoma is the most serious and dangerous skin cancer, due to its aggressiveness and tendency to grow fast and spread to other organs as metastasis. In association to other cutaneous tumours, melanoma accounts for 90% of the deaths (Garbe et al., 2010). MM is an overarching term for several types of malignant melanoma, which are divided in various groups, depending on their clinical and histological classification (Clark, From, Bernardino, & Mihm, 1969). The most common skin melanoma is superficial spreading melanoma (SSM) (Markovic et al., 2007), but nodular melanoma (NM) is the rapidest growing melanoma (Liu et al., 2006). SSM often begins with an intraepidermal horizontal or radial growth phase, as a macula that slowly evolves into a plaque with multiple colours, and can further develop nodular areas. The typical histological feature for SSM is the presence of pagetoid spread of clear malignant melanocytes throughout the epidermis. NM primarily starts as a nodular brown-black, often eroded or bleeding tumour in an aggressive vertical phase with short, or without any, horizontal growth phase (Markovic et al., 2007).
Other forms of less common melanomas are lentigo maligna melanoma (LMM), often located on the face and others parts of the body that have been sun-exposed for long periods, which is more common among elderly people, and acral lentiginous melanoma (ALM), an unusual form of cancer that often is located on the underside of feet and hands (Garbe et al., 2010). LMM and ALM will not be discussed further in this thesis, since they are uncommon and are less aggressive than other malignant melanomas. Cutaneous malignant melanoma is most often a visible skin cancer that can be easily cured if treated in time. As long as the tumour does not penetrate the membrane between epidermis and dermis, the melanoma is labelled in situ and should not develop metastases. About 90% of all melanomas are diagnosed as primary tumours, and their specific 10-year survival is 75%–85% (Garbe et al., 2010). Unfortunately, if the tumour continues to develop and grow deeper in the dermis, the cancer cells may come into contact with lymph and blood vessels, which may spread the tumour cells.

Breslow (1970) showed that tumour thickness plays a big role in prognosis, that is, the thicker the tumour, the higher mortality in MM (Balch et al., 2001). The so-called Breslow thickness is still one of the significant measures of melanoma and is important in the classification of melanoma tumours. Another measurement is the Clark level scale, which is the measure of deepness of the tumour’s growth in the cutaneous layers (Clark et al., 1969).

**Incidence**

MM is increasing in the whole world in white populations, especially where fair-skinned people receive excessive sun exposure (Garbe & Blum, 2001; Garbe et al., 2010). Australia (especially Queensland) has the highest incidence of MM. Lower incidence than in Australia, though still quite high incidence, is reported from New Zealand and North America, and also from Europe, where Switzerland, followed by the Scandinavians countries, such as Norway and Sweden, have the highest incidence (Curado et al., 2007). The reported incidence rate of MM in the world varies from 6–10/100,000 population in southern Europe and 10–14/100,000 population in Central Europe, to the USA with an incidence rate of 10–25/100,000 and Australia with 50–60/100,000 population, which is the highest reported incidence.

Sweden has one of the highest incidence rates of MM in Europe (Karim-Kos et al., 2008): the age-standardized incidence rate for 2007 was 26.5 per 100,000 for men and 24.0 for women. MM is one of the ten most common and rapidly increasing cancers in Sweden and is today in sixth place among cancers for both women and men. For men, the average increase per year is 4.4%, and for women 4.2% (National Board of Health and Welfare, 2011a).
Previous research has also confirmed that Sweden, and especially southern Sweden, has a higher prevalence of MM than the other Nordic countries (Moller et al., 2003).

Västerbotten County, with about 258,000 inhabitants (SCB, 2010), is a part of northern Sweden, and together with three other counties (Jämtland, Väster-norrland, and Norrbotten) included in the Cancer Registry for the northern region of Sweden. During 2010, 43 new cases of MM were diagnosed in Västerbotten County, and a majority of them were women (60%, n = 26). According to the National Board of Health and Welfare (2011a), the incidence rate in Västerbotten is increasing. In 2010 it was approximately 17.8/100,000 for women and 13.4/100,000 for men.

**Risk factors**

Except for sun exposure, the reasons for development of skin cancer are somewhat unclear and have been discussed as risk factors rather than causes. There is also ongoing discussion about the established versus the postulated risk factors and interactions between them.

People who have large numbers of common naevi, congenital (Slutsky, Barr, Femia, & Marghoob, 2010) and multiple, and/or atypical naevi are at the greatest risk to develop melanoma (Bauer & Garbe, 2003; de Giorgi et al., 2010; Markovic et al., 2007). The inheritability of melanoma is also of importance. We know that 5–10% of melanomas appear in melanoma-prone families (Bishop, Harland, Randerson-Moor, & Bishop, 2007; de Snoo et al., 2007; MacKie, Hauschild, & Eggermont, 2009). These families are defined as having an occurrence of invasive melanomas among at least two close relatives. In those familiar cases, genes with low prevalence/high penetrance are involved. In the typical phenotype of melanoma, among patients with pale Caucasian skin and red or blond hair and blue eyes, the high prevalence/low penetrance genes are involved (MacKie et al., 2009). Research about the melanoma susceptibility genes is a growing area and has revealed that one third of patients with MM have a germline mutation on the specific gene CDKNA2A, and also that this mutation is concentrated within certain geographic areas such as the Mediterranean area, Sweden, and Scotland (Pho, Grossman, & Leachman, 2006).

According to Bishop et al. (2002), the penetrance of CDKNA2A varies, depending on the geographic location, sun exposure, levels of pigmentation, and freckling, which means that environmental and behavioural factors may mediate the penetrance. Bishop et al. (2002) also stated that Swedish
carriers of the mutation have a higher estimated risk than other carriers in Europe.

Besides the genetic factors there are some exogenic factors that are associated with increasing melanoma. One of them is exposure to ultraviolet (UV) radiation from the sun, which is seen as the most important, and particularly, intermittent sun exposure (Lea et al., 2007). UV radiation has a carcinogenic effect on DNA, and thereby causes most tumours (El Ghissassi et al., 2009; Garbe et al., 2010; IARC, 2006a; Sivamani, Crane, & Dellavalle, 2009; Swedish Radiation Safety Authority, 2010). The geographical latitude plays a role for the development of CMM, and earlier studies have showed a negative correlation between latitude of residence and incidence of CMM (Armstrong & Kricker, 2001; Hu, Ma, Collado-Mesa, & Kirsner, 2004), which is presented as different distribution of MM in the world. North America, Australia, and Scandinavia are regions that have high incidences of CMM (Ferlay et al., 2008). However, when interpreting correlations between latitude and CMM incidence, it is important to take various genetic conditions into account and also to consider that types of skin cancer other than CMM are more common among different populations, for example, dark-skinned people (Byrd-Miles, Toombs, & Peck, 2007).

Artificial UV radiation from sun beds also adds to melanoma risk factors. Several studies (Lazovich et al., 2010; MacKie et al., 2009; Sivamani et al., 2009) have described the negative effect of artificial radiation as an additional risk, which is also stated by many experts groups (IARC, 2006a, 2006b; Swedish Radiation Safety Authority, 2010, 2011a). Sunburning episodes and chronic sun exposure are significant factors for developing melanoma and where an interaction between chronic UV exposure and the type of melanoma exists (MacKie et al., 2009; Whiteman, Whiteman, & Green, 2001). Thus, LMM is commonly found on constantly exposed body sites, while sunburning episodes at a young age are more often related to melanoma in younger ages (Whiteman et al., 2003). To conclude, the most CMM cases are caused by UV radiation, and the increasing incidence is probably related to the change of sun habits and sun exposure among people.

Socioeconomic status, occupation (Bränström, 2008), female hormones, pesticide exposure, risk for melanoma after renal transplantation (Bordea et al., 2004; Le Mire, Hollowood, Gray, Bordea, & Wojnarowska, 2006), therapeutic use of some pharmaceutics (e.g. NSAIDs), and the correlations to melanoma have been discussed during recent years (MacKie et al., 2009). Many studies have also shown that melanoma is more common among people with larger income and affluence (Pollitt et al., 2010; Shack, Jordan,
Thomson, Mak, & Moller, 2008), which may be related to larger opportunities for recreational sun exposure.

Mortality

The number of deaths due to cancer in Sweden in 2010 was about 25% of all deaths, and cancer was the second most common cause of death (National Board of Health and Welfare, 2010, 2011a). There is, though, a weak trend of increased mortality in melanoma, about 3.5/100,000 for women and 6.6/100,000 for men. The mortality in melanoma in the northern region is higher for men than women (OC North Region, 2008). In the Västerbotten County mortality is about 0.8/100,000 for women and 5.3/100,000 for men (National Board of Health and Welfare, 2010). MM accounts for 90% of deaths associated with skin tumours worldwide (Garbe et al., 2010). Since 1987 the mortality in MM in Sweden has increased about 20% for women and 40% for men, which means approximately 3.7 women and 7.0 men per 100,000 person (National Board of Health and Welfare, 2009). According to the oncological centre in the northern region (OC North Region, 2008) the age-standardized ratio in incidence of MM is still increasing for both sexes, but the age-standardized ratio in mortality in the same region remains relatively unchanged.

Diagnosis

Diagnosing MM at an early stage is essential to reduce mortality. People are advised to examine their skin by themselves in order to detect deviant skin changes. Most melanomas are discovered by patients themselves (Blum et al., 1999; Brady et al., 2000; Carli et al., 2004; Richard et al., 2000a, 2000b). However, physicians’ sensitivity to diagnosing melanomas is quite high, especially that of dermatologists (Richard et al., 2000b). The most common way to diagnose MM in health care is using visual examination. If nurses and physicians are observant and inspect different, irregular marks, they have a possibility of diagnosing MM. Optimally, a suspicious mark is excided and sent for histopathological analysis close to the onset. Visual diagnosing is appropriate and has high sensitivity if the physician has a long experience of MM and is exposed to more than ten cases per year (Lindelöf & Hedblad, 1994; Morton & Mackie, 1998). For professionals, tools such as ABCDEs (asymmetry, border, colour, diameter, evolving) and the Glasgow 7-point checklist for better diagnosing of MM (Grob & Bonerandi, 1998) have been available for several years. Other means of more sophisticated diagnostics are various kinds of dermoscopy and photography, either separately or combined. Dermoscopy has a greater accuracy in diagnosis of MM than the naked eye (Vestergaard, Macaskill, Holt, & Menzies, 2008), but
is yet not well integrated into clinical practice (Wurm, Curchin, & Soyer, 2010). Histopathological assessment has a great impact for further treatment and where assessment of tumour type and thickness, excisions’ adequacy, mitotic activities, and ulceration are included (Marsden et al., 2010; Regional Cancer Centre North, 2011). A well-performed excision is important in MM. Shaving or others biopsies are not recommended in MM, since they could influence accuracy of thickness assessment and other histopathological issues, and could influence treatment decisions (Garbe et al., 2010; Marsden et al., 2010). Commonly, the excision becomes a curative treatment, if the MM has not invaded the dermis. If the mark is large or is placed in a sensitive site such as the face, the patient is usually referred to a specialist surgeon.

**Treatment**

Swedish physicians are expected to follow a national MM care programme with recommendations on the most effective ways to treat melanoma (OC & Swedish Melanoma Study Group, 2007). These recommendations focus not only on primary and secondary prevention but also on care and treatment and follow-up for patients with suspicious marks and melanoma. The regional MM programme for the northern region of Sweden includes Västerbotten County and focuses on management and care based on the national MM programme. It contains diagnosis criteria, classification, and recommendations on how to treat melanoma (Regional Cancer Centre North, 2011).

A common procedure in Västerbotten when people initially seek care at a primary health care centre (PHC) is that the skin change either is primarily excided at the PHC or further referred to a specialist. Private skin clinics and a referral-free dermatological clinic at the hospital are also available for patients seeking care for melanoma. According to national and regional guidelines (OC & Swedish Melanoma Study Group, 2007; Regional Cancer Centre North, 2011) all melanoma thicker than 1 mm and tumours with ulceration or depth-level invasion equivalent to Clark IV or more, regardless of thickness, should be treated with wide excision following the primary excision. Furthermore, investigation and treatment of lymph nodes, so-called sentinel nodes, as well as other therapies are treatment in advanced MM. Surgery, if melanoma is diagnosed early, is still the only curative treatment of MM (Tsai, Balch, & Lange, 2010). Follow-up treatment focuses on detection of relapses and new MM, and is a secondary prevention. New pharmacological treatment of metastatic melanoma is under development and is demonstrating promising results (Chapman et al., 2011).
Prevention

Primary prevention is focused on supporting people to avoid sun exposure and burning episodes at early ages (Mujumdar et al., 2009; Whiteman et al., 2001). The typical advice for prevention of melanoma concerns recommendations about protecting the skin with clothing, using sunscreen such as protecting lotions, and exercising caution with sun exposure, since there are different UV indexes: to sum up, enjoy the sun, but do not get burned (Swedish Radiation Safety Authority, 2011b).

Screening and educational campaigns

An Australian intervention from the early 1980s—*Slip! Slop! Slap!*—has been adapted and spread around the world. This intervention prompted people to protect the skin from sun exposure by covering up with clothing, using lots of sunscreen, and wearing a hat. A following intervention from the UK was *Ugly duckling signs* (Doherty & MacKie, 1986), which focused on educating people about detection of the deviant skin marks. The Swedish *Sola sakta* [*Sun tan slowly*] from Cancerfonden and *Sola smart* [*Sun tan smartly*] from Apoteket (Bergenmar & Brandberg, 2003) focused on educating people about dangerous sun exposure and use of sun protection. Some interventions worldwide have resulted in increased knowledge and awareness of MM, and the MM incidence has decreased somewhat in the younger population (Karlsson & Fredrikson, 2007; Lindholm et al., 2004; Marks, 2004; Månsson-Brahme, Johansson, Larsson, Rutqvist, & Ringborg, 2002). However, many interventions have been insufficiently evaluated, and their effects are reported to be uncertain (Berwick, Erdei, & Hay, 2009). The incidence of MM has not decreased among older people (de Vries, Bray, Coebergh, & Parkin, 2003; Lasithiotakis, Petrakis, & Garbe, 2010; Youl et al., 2006).

Public MM programmes around the world during the past two decades have focused on increasing people’s knowledge about melanoma with the purpose of influencing them to seek care earlier in order to treat melanoma at an earlier growth stage. The Queensland melanoma project was among the first educational programmes in the world and has contributed to increased knowledge about MM (Marks, 2004) in Europe, as well. Some educational interventions in Europe have confirmed higher knowledge about melanoma, which has resulted in reduced patient delay and an increased proportion of patients with thinner MM and thereby better prognosis (Doherty & MacKie, 1986; MacKie & Hole, 1992). Swedish people’s knowledge about melanoma and risks related to intensive sun exposure is judged as high enough (Blum et al., 2007), but it has not led to a significant reduction of sun exposure and
incidence of melanoma (Bränström, 2003; Bränström, Kasparian, et al., 2010). Current studies have, though, reported only a tendency towards decreased incidence among younger (Karlsson & Fredrikson, 2007; Marks, 2004), but increasing incidence among older, people (Cho & Chiang, 2010; Lasithiotakis et al., 2010).

Screening programmes for melanoma remain insufficient in reducing melanoma-related morbidity (USPSTF, 2003). Screening efforts have concentrated on offering skin examinations, which have been popular both in the USA and Europe (Geller et al., 2003; Vandaele et al., 2000), and particularly in Sweden (Krynitz & Lindelöf, 2003; Paoli, Danielsson, & Wennberg, 2009). Melanoma Monday is a part of the ‘Euromelanoma’ project (www.euromelanoma.org), which is one example of screening interventions that have led to some degree of increased melanoma detection (Paoli et al., 2009).

Thus, efforts are put into screening, educational campaigns, and risk-reducing interventions to decrease mortality in malignant melanoma. The awareness of melanoma risks seems to increase initially after such interventions, but it soon falls into oblivion among many people. In Sweden, most people are aware that sun exposure increases the risk of getting skin cancer, but do not put that knowledge into practice (Bränström, Ullen, & Brandberg, 2004). Swedish people are foremost in the world with respect to exposure to UV radiation through sun tanning (Bränström, Kasparian, et al., 2010; Swedish Radiation Safety Authority, 2011a). Despite increased knowledge, many people continue to sunbathe, and the positive effect people experience from being in the sun seems to outweigh the perceived risks; the incidence of MM continues to increase, indicating that current campaigns are not effective enough (de Haas, Nijsten, & de Vries, 2010).

**Delay of diagnosis**

Delay concerns an extended time to diagnosis and is usually measured in days, when talking about cancer. Furthermore, delay can be divided into patient delay and health care service or provider delay, where both are included in the total delay (Hansen, 2008). Hansen et al. (2008) define delay as a period from first symptom to diagnosis or treatment. Delay of diagnosis of melanoma is defined as the time between the patient’s first awareness of a suspicious lesion to the excision (Richard et al., 2000a, 2000b). This delay can be viewed as the sum of the delay caused by the patient and the delay caused by health care professionals and the health care system. In some studies (Hansen, Vedsted, Sokolowski, Sondergaard, &
Olesen, 2011a; Hansen, Vedsted, Sokolowski, Søndergaard, & Olesen, 2011b; Lövgren et al., 2008; Murchie, 2007; Murchie et al., 2011; Olesen, Hansen, & Vedsted, 2009) health care delay is further divided into primary health care delay (caused by the primary care service up until referral to a specialist) and secondary health care delay (caused by the specialist health care service, from scheduling of the first visit through diagnosis to start of treatment). Factors of an organizational nature are difficult to isolate and analyse, because the organization as a part of the health care system depends on economic resources and other resources such as staffing; staff’s knowledge, assessment capacity, and skills; and also health care accessibility. Besides the organizational factors delaying MM treatment, adequate and evident policies and guideline are of importance in reducing delay. The complexity of the phenomenon delay makes it difficult to distinguish between the various agents and their contexts, since boundaries between them are fluid, and they thereby influence each other.

In this thesis, the delay of MM diagnosis is highlighted and focuses on patient delay and health care delay. Patient delay is in this thesis defined as the time between the first awareness of a suspicious mark and the first contact made with any health care professional. Health care delay is delay that is attributable to structural or other problems of the system of health care provision, that is, the service delivery. It is defined as the time between the patient’s first contact and diagnosis and treatment. In the literature on delay of diagnosis, most studies concern myocardial infarction. The scientific literature regarding delay of MM diagnosis mostly focuses on patient delay. However, reasons for patient delay in MM are not well explored in the existing literature. Furthermore, the health care–related delay in MM is not sufficiently highlighted in the literature; only a few smaller studies have been found.

**Health care delay**

Organizational problems as a reason for delay is hard to discern, and influences other aspects of delay. Patient flow is essential, and the delay depends partly on how patients physically move through the health care system and partly on how the—to patients—invisible services work and contribute to the delay (Hall, 2006). Delay between primary health care and specialist care is well-known and common in several countries (Murchie et al., 2011). Lacking information about where to seek care influences patients’ care seeking behaviour. The health care system signals an ambiguity about care seeking for skin changes. On the one hand, people are encouraged to seek care urgently when they discover a suspect melanoma. On the other hand, Swedish primary health care providers, particularly GPs, are burdened...
with limited opportunities to handle all patients urgently (National Board of Health and Welfare, 2011b). A difference between GPs in Sweden and GPs in many other countries is that in Swedish primary health care providers have more access to hospital investigations for patients with MM and also undertake greater numbers of investigative procedures within own practices; however, this also results in longer waiting times for GP appointments (Murchie et al., 2011). Doctor’s delay is mentioned in the literature and is sometimes hidden in the patient’s delay or the organizational delay. This kind of delay may include other health care professionals, such as frontline nurses work in, for example, reception and telephone counselling. Delay in referrals is another aspect of doctor’s delay. Doctor’s delay exists, but accounts for a smaller part of the health care delay before first excision of a melanoma (Richard et al., 2000a, 2000b). A high caseload further makes it difficult for professionals to be vigilant. GPs and primary health care nurses meet quite a few cancer cases every years, but hundreds or possibly thousands patients with symptoms which could be interpreted as a possible cancer. The situation in Sweden is similar to that in other countries in Europe (Olesen et al., 2009; Richards, 2009).

**Patient delay**

The concept patient delay is used in several contexts and diseases such as melanoma (Carli et al., 2004; Richard et al., 2000a; Schmid-Wendtner, Baumert, Stange, & Volkenandt, 2002), myocardial infarction (Isaksson, Holmgren, Lundblad, Brulin, & Eliasson, 2008; Johansson, Strömberg, & Swahn, 2004), and various forms of cancer (Andersen, Paarup, Vedsted, Bro, & Soendergaard, 2010; Jensen, Mainz, & Overgaard, 2002; Lövgren et al., 2008; Mitchell, Macdonald, Campbell, Weller, & Macleod, 2007). Some researchers have tried to explain why people do not seek care and why they do not attend screening programmes (Ackerson & Preston, 2009; Bergenmar, Törnberg, & Brandberg, 1997; Blomberg, Ternestedt, Törnberg, & Tishelman, 2008; Brandberg et al., 1996). Patient delay in melanoma is of particular importance for the prognosis of MM, since it exceeds the delay due to practitioner availability or response (Betti, Vergani, Tolomio, Santambrogio, & Crosti, 2003; Richard et al., 2000b), and it is the primary cause of mortality in melanoma. Although self-discovery is the most common way of detecting melanoma, patients with self-detected melanomas often wait for extensive time periods before getting a diagnostic confirmation (Blum et al., 1999; Carli et al., 2004). This phenomenon highlights the fact that patients not only need to be knowledgeable and capable to detect potential tumours; they also need to act upon this detection with an active, immediate physician-seeking strategy, rather than using passive coping strategies. From the literature we know that gender, age, and living
conditions influence patient delay. Women are reported to seek care earlier, as are younger people and those living in urban areas (Baade et al., 2006; Baumert, Plewig, Volkenandt, & Schmid-Wendtner, 2007; Blum et al., 2007; Marks, 2004; Richard et al., 2000a). Furthermore, awareness about seriousness influences care seeking. Preventive interventions have previously focused on increasing knowledge and awareness among people, but they seem to be quite insufficient to initiate care seeking behaviour (Bränström, Chang, et al., 2010; Bränström, Kasparian, et al., 2010).

**Care seeking behaviour**

**Symptom interpretation**

When discovering a suspicious mark, many people do not act immediately. Fear has an impact on the care seeking delay, but so does insecurity about the severity (Leydon, Bynoe-Sutherland, & Coleman, 2003). Schmid-Wendtner et al. (2002) have reported that an impression that a lesion was benign or not important delayed care seeking. Not wanting to burden or load the health care service unnecessarily, or having other personal and social obligations that are prioritized, may also influence care seeking (Andersen, Vedsted, Olesen, Bro, & Søndergaard, 2011; Leydon et al., 2003; Smith, Pope, & Botha, 2005). A review by O'Mahony et al. (2009a) of help seeking for cancer symptoms concluded that patient delay is a common phenomenon influenced by many factors, but particularly by symptoms. Symptom recognition, appraisal, and interpretation also influence people’s decisions to seek care (de Nooijer, Lechner, & de Vries, 2001a; O’Mahony & Hegarthy, 2009a). Bodily changes and sensations are something that many people do not interpret as symptoms of illness. Non-recognition or experiencing a low level of symptoms as reason for delay are described (Lövgren et al., 2008; Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009), and can result in a wait-and-see behaviour. The presence of more serious or alarming symptoms, and thereby increased likelihood of shorter delay, is described in other forms of cancer, such as colorectal cancer (Macleod et al., 2009; Mitchell et al., 2007).

Interpretation of symptoms is also influenced by the social context and everyday activities and is negotiated against them. Andersen (2010) found that experiencing bodily sensations and defining them as symptoms was not only considered as an unwanted break from normal life but also as a role transformation regarding social relations, obligations, and self-image. The process of recognition and interpretation of sensations as symptoms is complex. The significance of signs, and furthermore, the interpretation of
symptoms depend on the patient’s life history and situation, since the patient is both the experiencer and ‘assigner of understanding’ (Toombs, 1993). By using a wider life-world perspective, which gathers knowledge, bodily sensations, recognition, and interpretation into people’s life worlds (Toombs, 1993) we can better understand reasons for patient delay. Knowledge about cancer symptoms increases intentions to seek care, but even with knowledge, people delay (de Nooijer et al., 2001a; de Nooijer, Lechner, & de Vries, 2002). Care seeking or help seeking is a response to a change in health and a part of a more complex process of health-seeking behaviour (O’Mahony & Hegarthy, 2009a).

**Knowing where to seek**

Symptom interpretation is followed by a decision to seek care and a contact with the health care service. Unclear information, deterrents, and complicated ways of accessing health care providers do not make it easy to know how and where to seek. Such service access barriers increase patient delay. Particularly in rural areas, distances, transportation issues, and lack of user-friendly service hours delay care seeking and also participation in screening (Bergenmar et al., 1997; Brandberg et al., 1996; Byrne, 2008). In Sweden the primary health care centres function as a first point of access, where people can seek care without referrals; thus, it is important to solve scheduling problems (Byrne, 2008). A financially tightened health care organization and a heavy burden on staff in PHCs frequently makes it difficult for people to reach physicians and nurses by telephone and to quickly make appointments for assessment and diagnosis (National Board of Health and Welfare, 2011b).

**Coping with stress**

Coping strategies are crucial for the perception, interpretation, and subsequent response to stress, and necessary for maintaining stability and control in life, but vary depending on the stressor, the situation, the social context at hand, and personality disposition (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984; Snyder, 1999). Previous studies have described that people who are more worried and anxious more often participate in screening for MM (Brandberg et al., 1996). Some level of stress and threat is needed to motivate action, but action is influenced by many contextual factors (Bandura & Adams, 1977). In contrast, there are studies showing that stress, anxiety, and fear caused by threat could lead to denial and defensive avoidance, and thereby not promote positive health behaviour. Denying, redefining symptoms, and using self-care (medication or self-treatment), as well as struggling with fear, have been reported to delay care seeking
Coping is also correlated to motivation of preventive actions such as care seeking (Ruiter, Verplanken, Kok, & Werrij, 2003). Decision making to seek care is a complex process affected by the individual, but also by the decisional features or characteristics of the decision and other situational factors (Hunt, Krzystofiak, Meindl, & Yousry, 1989).

Janis and Mann (1977) have discussed stress in relation to decision making and use of various coping strategies during this process. Psychological stress is an unpleasant emotional state evoked by threatening events and stimuli. Stress symptoms appear when a person has to make a difficult decision that includes some distressing dilemma, and where one is forced to choose between somewhat unsatisfactory alternatives. The intensity of the stress reaction depends on the extent of losses the decision maker perceives will result from whatever choice she/he makes. The perceived level of stress will directly affect normal information processing and further the coping reactions. A moderate level (intermediate range) of emotional stress is suggested as the optimal degree when a person can be motivated to find a good solution to a problem. Low stress leads to insufficient concerns about risks, and is thereby not motivating. On the other hand, very intense stress leads to defensive avoidance or disruptive hypervigilance, which interferes with cognitive processes essential for making viable solutions (Janis & Mann, 1977).

**Theoretical frameworks**

**The Umeå model of nursing care**

The Umeå model of nursing care (Figure 1) could be seen as a scheme of the area where nursing care can be identified. In Figure 1 the model is described, and the papers included in this thesis situated. According to this model, the goal of nursing care and self-care is health. The model includes the two principal actors, the patient (P) (I–III) and the health professional (H) (IV). Health professionals are commonly connected to a care team (IV), while patients are connected to relatives (I–II). Nursing care consists of tasks and various kinds of actions, but also includes a patient–professional relationship, with the actors working in parallel (I–II, IV). Philosophy and ethics are foundations for research and care, since they influence performance and outcomes. Nursing care and research are performed in a care environment (IV), within a particular care organization (IV) and society (II) that also influence outcomes of care.
Life-world perspective

In this thesis I have tried to understand, interpret, and discuss people’s life worlds in relation to their illness experiences and patient delay. A life-world perspective on illness derives from phenomenology and concerns a person’s own understanding and lived world as experienced (Husserl, 1989; Toombs, 1993), which can differ from the normative medical health perspective. The lived body, connecting both the physical and the existential dimensions based on experience, is the usual view people have when they talk about body, health, and threats (Toombs, 1993). The experience of the onset of illness and its influence on daily life, own existence, and vulnerability—especially if the illness is serious and unexpected—affects the decisional process of seeking care. When people experience a threat such as a loss, they become acutely aware of the unpredictability in their lives and the possibility that things will not continue as they have in the past (Toombs, 1993).

Health belief model

The interpretations of the findings in this thesis (I–III) to a high degree follow the health belief model (HBM). The HBM is used as start point in
developing understanding and thoughts about people’s action when experiencing and interpreting a sign as serious. The HBM (Janz, Champion, & Strecher, 2002; Rosenstock, 1974) describes the process of motivation for lifestyles changes. According to the HBM (Rosenstock, 1974), there are several factors which facilitate a change in behaviour towards taking action to prevent a disease. A perceived threat is a sequential function of perceived severity and perceived susceptibility, that is, a heightened experience of severity is required before susceptibility becomes a powerful predictor for actual engagement in health-related behaviours (Janz et al., 2002). Janz and Champion (2002) express that a threat must be experienced as truly dangerous to lead to real action in health-related behaviours. Thus, the HBM describes that people, in order to act and change behaviour, must perceive a threat and a susceptibility to a disease, and further, they generally must be motivated to maintain good health. In addition, if they are exposed to appropriate cues to action and experience the barriers to taking action as manageable, they most likely will undertake risk-reducing behaviour (Macrae, Hill, St John, Ambikapathy, & Garner, 1984). The personal expectation resulting a person’s estimate that a given behaviour should lead to certain outcomes is self-efficacy. Self-efficacy is a concept defined by Bandura (Bandura & Adams, 1977; Bandura & Cervone, 1983) and was added to the HBM in 1988 by Rosenstock, Strecher, and Becker (Janz et al., 2002) as a crucial component in risk-reducing behaviour corresponding to our inner motivation. High self-efficacy signifies a resilient sense of efficacy that implies high assurance in the capability of approaching difficult tasks as challenges, instead of as threats to be avoided. People who doubt their capability shy away from such difficult tasks (Bandura, 1989).

One aspect missing in the health belief model is the interpersonal process influenced by different factors inside—and outside—the person, and also the time perspective of people that is ongoing during the decisional process to act or change behaviour. This model has also been criticized by others (Kirana, Rosen, & Hatzichristou, 2009) as missing the psychosocial perspective, since it was developed for use among people with rational thinking. The process of consideration of a sign and decision making to seek care is not a simple straight line. Many factors interplay with people’s reasoning, which is not presented in the HBM.

**Decision-making theories**

Many theories, such as the health belief model (Rosenstock, 1974), the theory of planned behaviour (Ajzen & Fishbein, 1980), the self-regulation model (Leventhal, Nerenz, & Steele, 1984), the conflict theory model (Janis, 1984; Janis & Mann, 1977), the transactional stress model (Lazarus &
Folkman, 1984), and Shaw’s (1999) framework of health behaviours, have been used to explain patient delay and patterns of help seeking. Since symptom recognition and its appraisals have influence on decision making to seek care, many studies also have tried to explain decision making by using different psychological dimensions, such as fear (Smith et al., 2005), level of awareness, individual propensity to avoid risky events, coping, and perception of health control (Forghieri et al., 2010), as well as individual coping strategies (Ruiter, de Nooijer, van Breukelen, Ockhuysen-Vermey, & de Vries, 2008). For this thesis I have chosen to focus on coping in decision making, that I consider is of particular importance for patient delay in MM.

Coping in decision making

Affective, cognitive, and behavioural aspects are all of crucial concern in the psychology of crisis and stress management (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Lazarus & Folkman, 1984). Coping as a psychological concept is related to these aspects. Coping is much debated as to whether it is seen as a trait of the individual, that is, a stable, characteristic feature, or is influenced by dynamic situational factors, becoming a process (Zeidner & Endler, 1996). Janis and Mann (1977) state that, during decisional conflicts caused by threat and threat-evoked emotions, the cognition is boiling hot, and the emotions will strongly influence the judgements and actions undertaken. In situations when a serious threat appears, information processing is crucial for carefully preparing a decision, which is characterized by a thorough information search and unbiased assimilation of new information. This is possible if vigilance is the pattern of coping behaviour. Other coping patterns that may occur when one has to manage threats are hypervigilance, defensive avoidance (buck passing and procrastination), unconflicted change, and unconflicted adherence, five basic patterns described in the conflict theory model (Janis, 1984; Janis & Mann, 1977). In this thesis, paper III focuses on coping in decision making.

Conflict Theory Model

Decision making is a complex cognitive process which involves major sources of stress (Janis & Mann, 1977). According to Janis (1984), HBM fails to specify the crucial conditions that determine when people will use a vigilant decision making pattern and when they will use maladaptive (defensive and hypervigilant) patterns of coping. The HBM is not viewed as incorrect, but it applies only to a limited aspect of decision making, namely, when people are acting in a vigilant pattern of coping (Janis, 1984). Janis and Mann state that in order to make a careful, sound decision of importance for the future, much is required from the decision maker. A
stable decision is connected with a high degree of selectivity. There are risks of becoming overloaded with information, leading to uncertainty and decisional dilemmas, and thereby risks of making wrong choices, whatever course is chosen. Janis and Mann (1977) also highlight other aspects such as relevance of information and correct assimilation that may influence the decision making. Janis and Mann (1977) have emphasized that humans should not be seen as rational calculators, always choosing the best solutions without decisional conflicts and stress emerging from those. Instead, a human should be seen as one who could be ‘beset by conflict, doubts, and worry, struggling with incongruous longings, antipathies, and loyalties, and seeking relief by procrastinating, rationalizing, or denying responsibility for own choices’ (Janis & Mann, 1977,15).

The timeline and various stages of the decisional process influenced by stress and time are highlighted in the conflict theory model (Janis & Mann, 1977). In the process of making a stable decision by using vigilant coping patterns, people pass through five different stages: appraising the challenge, surveying alternatives, weighing alternatives, deliberating about commitment, and adhering, despite negative feedback (Janis, 1984; Janis & Mann, 1977). In other words, when a course of action is challenged, a person starts to search for alternatives, and then moves to the stage of carefully weighing advantages and disadvantages of the alternatives, which includes information seeking and consideration of the possible consequences. After coming to a tentative decision carefully based on all the information gathered, one comes to a final choice when an additional re-examination of all information will be done before the commitment and adherence to a current course occur.

**Gender theories**

The thesis focuses on gender differences in decision making to seek care. These findings are interpreted using gender theory, since health-related behaviour among men and women could be explained this way. Although many sociocultural factors are correlated with health behaviour, gender is one of the most important. Generally, men and women do not differ from each other except for the biological differences, but the socialization process regarding their bodies and the view of health and diseases in relation to women and men have importance for the distribution of different diseases (Connell, 2003). Men in general have significantly less healthy lifestyles than women, and being a woman may, in fact, be the strongest predictor of health-promoting behaviour (Courtenay, 2000). The symbolic meaning of being women or men as a gendered dimension of the normative expectations
is relevant for peoples’ behaviour, since the societal structured meanings are something that individuals are exposed to during their lives (Connell, 1995, 2003). Such aspects shape people’s thoughts and behaviours. Annandale (2003) further explains the changes in incidence and mortality trends in relation to changed gender patterns. As an example, she highlights the increasing incidence of MM among men as a consequence of a gendered behavioural change, whereby a previously typically female behaviour of sun tanning has become increasingly evident also among men. Furthermore, she explains that, despite a comparably similar level of awareness about UV radiation risks, men are less likely to use sunscreen and other protection, and consequently, more often get unhealthy sunburn. At the same time it should be noted that men have worse prognosis than women and that the skin melanoma death rate in Sweden is nearly twice as high as for women (National Board of Health and Welfare, 2010; 2011a).

It is useful to examine gender constructions when identifying various behaviours related to malignant melanoma, coping, and decision making. Societal development affects the views of gender. In turn, views on gender affect global health and the distribution of various diseases in the world. Gender constructions affect body image and also lead to changes of different gender-stereotypical patterns of behaviour (Connell, 2003). In a stereotypical masculinity identity control, competitiveness, aggression, reason, and emotional reticence are seen as natural attributes of a man (Edley & Wetherell, 1995). In stereotypical masculine behaviour it is important not to show weakness, hypochondria, or a lack of traits believed to signal masculinity. Such stereotyped patterns characterize western society and shape current societal norms (Chapple, Ziebland, & McPherson, 2004). While masculinity entails being strong, firm, protective, and active, a stereotypical femininity entails being worried, dependent, pleasant, thoughtful, and accommodating (Nikolajeva, 2004). Women as a group usually seek care more often, which may also carry a risk of being stamped as hypochondriac or neurotic, and thereby delay their care-seeking, so that health care is seen as a ‘last resort’ (Hunt, Adamson, & Galdas, 2010). On the other hand, men’s reluctance to seek care may be related to traditionally masculine roles emphasizing emotional control, self-reliance, and power (Addis & Mahalik, 2003).

Different aspects, such as masculinity including stoicism as a normative rule of not showing vulnerability, have been used to explain the adverse effect on men’s health and their claimed reluctance to seek care (Addis & Mahalik, 2003; Emslie, Ridge, Ziebland, & Hunt, 2006; Galdas, Cheater, & Marshall, 2007; Galdas, Johnson, Percy, & Ratner, 2010).
Rationale for the thesis

The importance of earlier discovery of MM is pointed out even by administrative authorities such as the National Board of Health and Welfare in Sweden (2011a) and the Swedish Radiation Safety Authority (2010), as well as by providers within health care organizations, which have had a crucial role in prevention and interventions influencing discovery of melanoma. Studies about cancer survival in Europe show that numerous deaths could be avoided, if the cancer was diagnosed earlier (Abdel-Rahman, Stockton, Rachet, Hakulinen, & Coleman, 2009). In Denmark and UK the research about delay of cancer diagnosis has led to political decisions and reorganization of the health care system in order to improve survival (Olesen et al., 2009; Richards, 2009). However, melanoma incidence is still increasing in Sweden (National Board of Health and Welfare, 2011a). Many studies show that delay in care seeking is the most crucial factor contributing to diagnosis delay and that presentation with cancer symptoms is not a straightforward or linear process towards diagnosis and treatment (Macleod et al., 2009; Richard et al., 2000a).

Prevention programmes seem to have a short effect and do not often reach or attract those at higher risk for melanoma (Baumert et al., 2007; Brandberg et al., 1996; Bränström, Chang, et al., 2010). Evidence of an expanded understanding of different factors influencing people’s help-seeking behaviour, such as psychological and sociological factors, is needed. Studies on decisional processes for care seeking are sparse, and particularly among people with malignant melanoma. Patient delay in lung cancer and myocardial infarction, as well as colorectal cancer, has been studied (Isaksson et al., 2008; Johansson et al., 2004; Lövgren et al., 2008; Mitchell et al., 2007). Research on patients’ life-world perspectives of illness is in general lacking in the MM patient group. Delay and its complexity need to be highlighted in order to understand where and how people can be influenced to seek care earlier for suspect melanoma. Such knowledge would offer opportunities to further develop and refine intervention programmes. There is also a need to explore shortcomings in health care organization for MM patients to decrease the delay caused by the health care system.
**Aims and objectives**

The general aim of this PhD thesis was to explore reasons for delay in care seeking, diagnosis, and treatment of malignant melanoma. The specific objectives addressed in the respective studies were

**Study I:** To explore patients’ decision making about seeking care for malignant melanoma.

**Study II:** To identify specific patterns in the decision-making process to seek care for suspect melanoma, as narrated by women and men.

**Study III:** To compare self-reported decision making coping styles between men and women in various ages, who live with or without a partner and who diagnosed with various stages of malignant melanoma in northern Sweden.

**Study IV:** To describe and compare patients diagnosed with MM, depending on their initial contact with care, and with regard to age, sex, and MM type and thickness, and to explore pathways and time intervals between clinics from the initial contact to diagnosis and treatment.
Methods

Methodological assumptions

The methodological assumptions that guided the thesis were pragmatism and a combination of various methods.

Pragmatism

The contemporary American sociologist David Morgan, influenced by John Dewey (Morgan, 2007), describes pragmatism as a new paradigm that rejects the epistemological dualism between relativism and realism (Table 1). Dewey had strong Hegelian influences, and referred to his philosophy as instrumentalism. This philosophy was developed from his belief in an empirically based theory of knowledge, becoming associated with the newly emerging philosophy of pragmatism. According to Dewey, self-action is a pre-scientific concept of power which humans possess of their own and which initiates and causes their actions. Experiential education, which nowadays has been translated and seen as quite synonymous with problem-based learning, places the learner in the active role of researcher. Teachers and educators should focus on facilitating and guiding, not only delivering information (Dewey, 2009, 217-218).

Morgan views it as a benefit that this new paradigm of pragmatism treats research as a concrete act of doing rather than an abstract act of knowing. The goal of a pragmatic paradigm is to give equal attention to studying epistemology (theory) and methods (practice). Furthermore, he states that pragmatism places a greater emphasis on research that pursues practical goals. Theory generating and theory oriented-research are toned down in favour of practice-oriented research and linking theory and practice together to a greater extent. Table 1 gives an overview of the traditional view of various research approaches and is a rejection of the epistemological dualism of relativism versus realism (cf. Morgan, 2007). Morgan states that we need to give equal attention to studying methods, methodology, and epistemology. Further, he states that we need to use our study of methodology to connect issues in epistemology with issues in research design, rather than separating our thoughts about the nature of knowledge from our efforts to produce it (Morgan, 2007, 68).
Table 1. Traditional views of qualitative and quantitative approaches in research, completed with a pragmatic approach (adapted from Morgan, 2007).

<table>
<thead>
<tr>
<th>Studies</th>
<th>Qualitative approach</th>
<th>Quantitative approach</th>
<th>Pragmatic approach</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Epistemology</strong></td>
<td>Constructivism/Relativism</td>
<td>Objectivism/realism</td>
<td>Pragmatism</td>
</tr>
<tr>
<td><strong>Connection of theory and data</strong></td>
<td>Induction</td>
<td>Deduction</td>
<td>Abduction</td>
</tr>
<tr>
<td><strong>Relationship to research process</strong></td>
<td>Subjectivity</td>
<td>Objectivity</td>
<td>Intersubjectivity</td>
</tr>
<tr>
<td><strong>Inference from data</strong></td>
<td>Context</td>
<td>Generality</td>
<td>Transferability</td>
</tr>
</tbody>
</table>

By using a pragmatic approach in this thesis, I give equal attention to methods, methodology, and epistemology, and use the study of methodology to connect issues in epistemology with issues in research design, rather than separating thoughts about the nature of knowledge from the efforts to produce it (cf. Morgan, 2007, 68). At the annual meeting of the American Educational Research Association in 1994, Yu stated the following which I agree with and use in my interpretation of data.

**Knowledge is a result of inter-subjectivity. I am a part of reality, and reality is a part of me; truths carry perspectives, and perspectives contain truths. The world I know is partly shaped by my input, and being who I am is partly caused by the input from the world. In this sense, there isn’t a reality entirely independent of human inquiry; neither a perspective without the influence from the world (Yu, 1994).**

**Combined qualitative and quantitative methods**

In this thesis I use both quantitative and qualitative approaches in accordance with a pragmatic view of truth, and in order to describe and explore the phenomenon of delay in relation to MM. Since delay is a complex phenomenon, it is appropriate to apply different methods in order to explore various factors influencing delay and health (cf. Morgan, 1998). On the other
hand, it is difficult to combine different methods, due to differences in ideas about the nature of knowledge and its generation. In this thesis I combine methods and view it as a strength (cf. Morgan, 1998). It is possible to put qualitative research results into practice in clinical settings for quantitative evaluation. Connecting different methods and their different strengths can help health researchers to address the complexity of research topics, particularly if they are applied in practical settings (Morgan, 1998).

**Settings and participants**

The studies in this project were performed within Västerbotten County (I–II, IV), complemented with three other counties, Västernorrland, Norrbotten, and Jämtland (III), together representing the northern region of Sweden. Table 2 is an overview of the sampling and participation in studies I–IV.

<table>
<thead>
<tr>
<th>Studies</th>
<th>Invited (n) Women/Men</th>
<th>Included (n) Women/Men</th>
<th>Mean age (yrs) Women (SD)/Men (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>24</td>
<td>21</td>
<td>57.5 55 (15.4)/61 (13.0)</td>
</tr>
<tr>
<td></td>
<td>12/12</td>
<td>11/10</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>36</td>
<td>30</td>
<td>55.5 55 (15.2)/56 (14.9)</td>
</tr>
<tr>
<td></td>
<td>16/20</td>
<td>15/15</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>437</td>
<td>270</td>
<td>61 58 (14.4) / 63 (11.9)</td>
</tr>
<tr>
<td></td>
<td>219/218</td>
<td>133/137</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>123</td>
<td>71</td>
<td>57.9 55 (13.5)/61 (12.2)</td>
</tr>
<tr>
<td></td>
<td>68/55</td>
<td>38/33</td>
<td></td>
</tr>
</tbody>
</table>

Participants were identified through the computerized medical records within the clinical diagnosis register, and additionally through the Swedish North Region Cancer Register (I–IV). The participants (I–IV) from Västerbotten were treated at the dermatological clinic and other clinics at Umeå University Hospital (Norrlands Universitetssjukhus, NUS), and at various health care centres in the health care district. The procedure of MM care in Västerbotten is described above in the background section under Treatment.

**Sampling**

In study I inclusion criteria were being Swedish speaking, aged 18–80 years, and diagnosed with MM in situ, NM, or SSM during the latest two years in 2007–2009. Twenty-four people were consecutively sampled from the
diagnosis register in the computerized patient record system at either the dermatological clinic of NUS in Umeå or at two health care centres. Three patients declined for personal reasons (12.5%). Twenty-one people participated: 11 women (mean age 55, SD 15.4) and 10 men (mean age 61, SD 13.0).

In study II, we used the data collected in study I, but invited twelve further participants of whom three declined. They were also recruited from the computerized patient record system at a dermatology clinic and from the Swedish North Region Cancer Register. The sample was based upon an effort to get a diverse sample, in the literature labelled as maximal variation sampling (Polit & Beck, 2009). The sample included participants in various ages, sexes, and living areas, that is, rural and central. Of the 30 participants included in study II, 15 were women (mean age 55, SD 15, 2) and 15 men (mean age 56, SD 14, 9). Inclusion criteria were being Swedish speaking, aged 18–80 years, and diagnosed with MM in situ, NM, or SSM during the latest two years between 2007 and 2010.

In study III, 437 participants from the Swedish North Region Cancer Register were identified and asked for participation. Inclusion criteria were 18–80 years old, being diagnosed with MM in situ, NM, or SSM during the latest 3 years in 2008–2010. The sample size was based on the participant–item ratio 5:1 (Hatcher, 1994). Of the 437 eligible participants 273 (62.4%) accepted participation and filled in the questionnaire but three were excluded due to missing data. The data from the register regarding tumour type and thickness were merged with the questionnaire data. A flow chart of the inclusion and participation in study III is presented in Figure 2.

In study IV, a sample of 123 eligible participants living in Västerbotten, identified through the Swedish North Region Cancer Register, was invited and 71 of them participated. The inclusion criteria were being 18–80 years old and diagnosed with MM in situ, NM, or SSM during the latest 3 years in 2008–2011, but not diagnosed with MM more than once. Data from patient records regarding the clinical pathways were used. The inclusion and participation in study IV is presented in Figure 2.
Data collection

Participants in studies I and II were invited by letter to participate in an interview. They could choose the place and time for the interview. The interviews were tape-recorded and transcribed verbatim to text. Most interviews were performed in the participants’ homes, and some at health care settings. The interviewer had not met participants before and had no relation to them as caregiver. For study III, questionnaire data were collected by letter. The questionnaire was delivered together with information, informed consent form, and a pre-paid envelope. They were asked to send back the questionnaire if they wanted to participate. They were also asked to fill in supplementary questions regarding age, sex, and living conditions. For study IV, participants from Västerbotten in study III were also asked to give consent for the researchers to obtain data from the participants’ personal medical records regarding clinical pathways during the diagnosis process of MM. Data regarding clinical pathways were analyzed in study IV.
In Table 3 an overview of methods for data collection and analyses is presented.

Table 3. Overview of design, methods, and participation

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Data collection</th>
<th>Period for data collection (Yrs)</th>
<th>Method of analysis</th>
<th>Participants (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>2008–2009</td>
<td>GT</td>
<td>21</td>
</tr>
<tr>
<td>II</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>2008–2010</td>
<td>QCA</td>
<td>30</td>
</tr>
<tr>
<td>III</td>
<td>Quantitative, cross-sectional</td>
<td>Questionnaire</td>
<td>2011</td>
<td>Statistics</td>
<td>270</td>
</tr>
<tr>
<td>IV</td>
<td>Quantitative, cross-sectional</td>
<td>Register and record studies</td>
<td>2011</td>
<td>Statistics</td>
<td>71</td>
</tr>
</tbody>
</table>

GT = Grounded Theory; QCA = qualitative content analysis

**Interviews**

Semi-structured interviews (Kvale, 1997) of a narrative nature, which is a special form of communication between the interviewer and the participants, were performed in studies I and II. Interviews are special situations in which the interviewees offer a piece of their own lives, and this helps us to understand their life worlds. Mishler (1991) states that an interview is a special speech event with some expectations, but also an outcome of interaction and context. The participants in studies I and II were, according to the aims of the studies, telling about their experiences and thoughts in the decision-making process to seek care for MM. An interview guide was used, covering such areas as discovery of the mark, thoughts about MM, aspects influencing decision making to seek care, how participants sought care, and perceptions of health care providers’ reception and support. The opening questions were: ‘Please tell me about when you first noticed the change or lesion in your skin. How did you first think about seeking care for the skin change?’ Furthermore, ‘Could you remember if there was anything in particular that delayed your decision? Please tell me about your feelings and thoughts when you finally decided to contact a clinic.’ The answers were followed with probing, such as ‘Please tell me more about that’. The interviews in studies I and II lasted between 45 and 90 minutes. All
interviews were tape-recorded and transcribed verbatim and validated for analysis.

**Questionnaire**

The Melbourne Decision Making Questionnaire (MDMQ) covering the decision making process was used in study III. MDMQ is a questionnaire developed by Mann et al. (1997) and consists of two parts, where the first six items concern the subscale *self-esteem*, and the later part with 22 items concerns the four subscales for the coping styles *vigilance*, six items relating to different steps in a sound decision-making; *hypervigilance*, five items relating to decision making under pressure; *buck-passing*, six items, and *procrastination*, five items, both measuring aspects of defensive avoidance. The items were answered on a three-point Likert scale (0 = not true for me; 1 = sometimes true; and 2 = true for me). The higher the scoring on a subscale, the higher the correlation to a specific coping style. The subscale vigilance was hypothesized to represent the most effective and rational coping strategy associated with moderate stress. The defensive (buck-passing and procrastination) or hypervigilant subscales were hypothesized to represent less effective coping strategies, that is, either avoidance or emotional excitement associated with severe emotional stress (Mann et al., 1997).

The questionnaire has been tested in various contexts in some western countries such as the USA, Australia, and New Zealand, and also in some European countries (the Netherlands, Spain, and Turkey). The tests of reliability of subscales in different countries have shown the following Cronbach’s alpha: self-esteem 0.74; vigilance 0.65–0.80; hypervigilance 0.61–0.74; buck-passing 0.77–0.87; and procrastination 0.70–0.81 (Bouckenooghe, Vanderheyden, Mestdagh, & Van Laethem, 2007; de Heredia, Arocena, & Gárate, 2004; Deniz, 2006; Mann et al., 1997; Mann et al., 1998; Sari, 2008). A Swedish translation was performed by the research group, then back-translated by an authorized translator and accepted by the authors. The trustworthiness of the translated instrument was tested. Some minor changes in the wording of some items between the English version and the translated Swedish version were done during the process of evaluation. Some items were reworded somewhat due to cultural differences in interpretation. People in northern Sweden are apprehended to be less outspoken and to not use overstatements. Terms such as ‘tremendous’ were toned down, since some people avoided answering these items in a pilot study. Cultural sensitivity is of importance to consider in translations of questionnaires, and we tried to follow conceptual, item, and semantic equivalence during the process of questionnaire adaptation (Streiner & Norman, 2008). A group of pilot readers with various experiences of working
within health care (two nurses, two psychologists, and one physician) were consulted to evaluate the face validity and reliability of the items and some minor adjustment of wording in items was made. The questionnaire was tested twice among various groups of health care students and health care workers and teachers at the nursing department of a University. Factor analyses were performed, and a solution with a four-factor model was assumed as appropriate. The Cronbach’s alpha for the Swedish translated version of MDMQ in this sample was: self-esteem 0.70; vigilance 0.72; hypervigilance 0.63; buck-passing 0.72; and procrastination 0.75 (III).

**Register data and medical record data**

Data regarding tumour type and thickness, date of diagnosis, diagnosis clinic, and identity was collected from the National Quality Register for Melanoma of Skin of the northern Swedish region. The completeness of the register is reported to be about 94% - 100% (Regionalt Cancercentrum Linköping & The Swedish Melanoma study-group, 2008, 2011). Data regarding patients’ pathways between clinics within the health care service and completing data regarding tumour thickness were collected from patients’ medical records. Register data were analysed in study III together with questionnaire data, and in study IV together with medical records data. The register data were also used as a starting point in exploring patients’ clinical pathways, since the reporting clinic is registered there.

**Data analyses**

**Grounded Theory**

Grounded Theory (GT) is a systematic generation of theory from data containing both inductive and deductive thinking (Charmaz, 2000; Glaser & Strauss, 1967). The GT analysis (I) was started simultaneously with data collection by repeatedly listening to the tape-recorded interviews and a simultaneous preliminary interpretation. Notes, ideas, and new questions emerged during this process and were written down and further discussed among the researchers close to the interviews. This process of going back and forth between data collection and collected data was important to increase the researcher's sensitivity to new shades of meanings, ideas, and questions. After all interviews were transcribed and read several times, a preliminary understanding of all interview text was made and compared with notes and ideas from the previous phase. The content was written down and arranged in domains and categories in a mind map. The process of coding, as a link between data collection and emergence of the theory
(Charmaz, 2006), was then started. The open (initial) coding, when some segments of data were taken apart and named with a concise term (keeping the meaning) was done as a first step in the analytical process of developing abstract ideas from interpreting each segment of data. Codes were brought together by creating tentative categories of items with similar content. A continued process of constant comparison of data is necessary, due to the various levels of the codes and categories, in order to get a theory emerging from the data (Glaser & Strauss, 1967). Further, the codes were related to each other and organized into categories, still emerging from data, but incisively and completely categorizing the data. A core category was identified. Through analysis and conceptualization of the relationship between the categories a hypothesis emerged about how the categories interacted with each other and with the core category. According to Glaser and Strauss (1967), a relation between the core category and the other categories should be found, if the categories have grown up from data. The analysis followed the GT-process as described by Glaser (1967), but with interpretation highly influenced by the researcher (Charmaz, 2000), since this process of interviewing is an active process between interviewer and interviewees (Kvale, 1997). A clear relation was found between the core category and the other categories. The theoretical coding, where relations between the categories are explored and organized into a model, is labelled as connecting data (Charmaz, 2006). A new version of the previous mind map emerged and became a model of the factors that patients attributed as reasons for their delay in care seeking.

**Qualitative content analysis**

Content analysis (QCA) is a method for analysis of texts and can be performed in a quantitative or qualitative manner. I have used qualitative content analysis (Krippendorff, 2004) in study II. According to Graneheim and Lundman (2004), QCA starts with thoroughly reading the text, that is, the unit of analysis, and then systematically following some analytic steps in order to describe categories and/or themes describing the content expressed as variations or threads. The steps that I followed were (1) identify meaning units; (2) condense them, which means that they are shortened but still keep the core content; (3) assign each meaning unit a labelling code describing the content; and lastly, sort the codes based on differences and similarities and organize them into groups on levels of abstractions forming subcategories and categories. Threads of meanings between categories on various levels were identified as themes. Discussions between the authors during all steps in the process were essential to the trustworthiness of the analysis. The QCA process is a movement forward and backward, from original text to analysed
data, aiming to compare, discuss, and come to agreements, intended to strengthen the credibility of the analysis and findings.

**Statistics**

Descriptive statistics were used in studies III and IV to describe the characteristics of the population. For all analyses, the Statistical Package for the Social Sciences (SPSS, ver. 18.0 Chicago, IL, USA,) was used. A p-value <0.05 was chosen as the level for significance.

In study III, I used a questionnaire. Internal missing values up to 10% were accepted and replaced (n=8) with mean values calculated on an individual’s subscale levels, which has proved to be an appropriate method (Shrive, Stuart, Quan, & Ghali, 2006). By using Person’s coefficient we calculated correlations between self-esteem, other coping styles, and other variables. For the statistical analysis of group differences, participants were categorized into groups, according to sex, tumour type, tumour thickness, and age. For categorical variables Chi-square tests (χ²) were used, and for continuous variables Student’s t-tests were used. To explore scoring differences between groups we used analysis of variance (ANOVA). The Bonferroni procedure was applied to control for multiple testing.

In the analysis of study IV the participants were organized into groups, depending on their initial clinic contact. Also tumour thickness, age, and sex were compared. Clinic group was labelled as either PHC, including patients who had sought care at the primary health care centres from Västerbotten County, or Derm, including patients who had sought care at the public dermatological hospital clinic, other hospital clinics, and private skin clinics. Chi-square tests were used for categorical variables to explore group differences based on sex, median age, tumour thickness, and tumour type. Tumour thickness of 0.70 mm was established as cut-off, since in the literature it has previously been used as a limit for labelling MM as thin or thick (Lomuto, Calabrese, & Giuliani, 2004). Analysis of time intervals was performed using the Mann Whitney U test and by presenting mean and median distributions, since the groups were small and the variable had a skewed distribution.

**Methodological considerations**

I have tried to use different methods to describe delay from different perspectives and to obtain a more complete picture of it. I am aware that interview situations leave a possibility for co-creating, due to the interaction
between two people, but it may not been seen only as a weakness (Kvale, 1997). In accordance with GT (Charmaz, 2000) and quality of interview (Kvale, 1997), I used probing questions to get a deeper understanding of the manifest construct of delay. Similarly, the qualitative methods were appropriate, since the purpose was to describe the delay and the reasons behind it (Sandelowski, 2000).

Another issue is the trustworthiness, which I have reflected on during the whole time. It is important to remember that all research is contextual and that results would be reflective of the context. Some results are applicable more specifically to Västerbotten’s context, while some are applicable in the general field. The impact of symptom interpretation, as a part of delay in care seeking when suspecting illness, is transferable to other contexts with regard to aspects of experiencing existential threat to life. Patient delay is common but aspects such as knowledge, access to health care, geographical distances, and socio-economic status are significant for delay. Those aspects are lacking in this thesis and would implicate further research based on it.

**Sampling**

In study I, Grounded Theory was used as the analytic method, since the intention was to identify social processes. When I started the data collection, I hoped to make a theoretical sampling over time. However, the intended data collection from health care centres became impossible, due to insufficient melanoma diagnosis registration. Instead, a majority of the patients were sampled at one moment from the dermatological clinic, which possibly may be a bias.

Reported reasons for non-participation in the qualitative studies (I–II) were mostly personal, for example, being tired or lacking time. The highest non-respondents rate was found in studies III and IV. Reasons for declining participation in these quantitative studies (III–IV) were quite unclear, since we did not ask for any explanation, due to ethical considerations. It is possible that these participants in a higher degree did not feel well, or found it difficult to fill in the questionnaire. Another reason for non-participation in study IV was a concern for integrity, since we asked for permission to check medical records. Some participants commented that they did not think that the data in medical records corresponded with their manner of help seeking, and that their desire and efforts to get in contact with health care services had not been registered. One methodological aspect contributing to no participation in study IV was that data collection for studies III and IV was done in parallel. The limited sample size in study III was a cause of concern, but the results are regarded as theoretically significant (cf. Janis &
Mann, 1977) and in line with results from previous studies (Bouckenooghe et al., 2007; Brown, Abdallah, & Ng, 2011; Mann et al., 1998). However, the small samples in studies III and IV might be reasons for not reaching significant levels to a higher degree (Kramer & Rosenthal, 1999).

**Retrospective approach**

The procedures during care seeking and diagnosis are sometimes normally drawn out, since diagnosis may be unsure for a period. This aspect influences the total time for diagnosis, but must not prolong or delay the diagnosis. Another difficulty with a retrospective approach in delay studies is that people do not report delay in terms of the duration of the delay. Instead, they report their responses to signs and symptoms. A retrospective approach makes it difficult to evaluate the delay, since people know more about the diagnosis when reporting about delay than at the time for delay. There is a loading of normative values linking the responsibility to patient delay to the patient as an individual. The negative tone in the term delay implies that patients—delayers—behave improperly, which is not true. We know that only a small proportion of patients have alarming symptoms, and these do not always become alarming immediately, especially if they are vague (Blum et al., 1999; Macleod et al., 2009; Swetter et al., 2009a). The symptomatology of melanoma, and also other cancers, is complex, which makes it difficult to interpret symptoms (Svendsen et al., 2010). Appraisal of delay can be biased, since it is influenced by the context. Treatment delay can be influenced by people’s behaviour, both as care seekers or care providers, and the time spans in the process of diagnosis do not exactly represent the actual delay. On the other hand, there is no more appropriate way to collect such data. Prospective approaches would be preferable, but hard to implement. Delay contributes to mortality, but is difficult to explore, since the context influences the delay. Furthermore, a retrospective approach in research makes it difficult to exactly specify the real length of the delay. Studies concerning the interpretation of symptoms are important to get more knowledge about how people behave when discovering a sign and how this knowledge can be used to develop better preventive programmes to get people to seek care earlier. It is also vital to develop better instruments for estimations of delay.

**Ethical considerations**

The project was approved by the regional ethics board in Umeå (Dno 08–070M). Ethical issues are important when studying people in vulnerable states. Having a diagnosis of MM is related to existential concerns and emotional load. My intentions have been to avoid adding to the burden by
being sensitive to such expressions. However, during interviews I have experienced the opposite, that is, people have expressed satisfaction at being asked and getting an opportunity to tell their stories. An experienced psychologist was involved in the project to help with debriefing, if needed, but was never requested. In general, I view the benefits of the study as exceeding the inconvenience.

**Results**

**A model of patient and health care delays**

The delay of diagnosis and treatment includes both patient delay and delay within the health care system. The patient delay precedes care seeking, and thereby also the health care delay. Both parts of delay can be seen as a time-consuming, ongoing process and are in this thesis described as an hourglass, in Figure 3, where the upper part visualizes the patient delay. The middle visualizes the moment of care seeking and the lower part the health care delay, including pathways and referrals. How fast the sand flows depends on the width of the neck and the quality of the sand. The delay could be described similarly. The total delay includes processes such as patients’ interpretation, negotiation, and decision-making/action, and the management of patients in the health care service (I–IV). The process starts within the patient with discovery of signs that must be perceived. Knowledge and awareness of signs, but also uncertainty, influence not only detection but also how one perceives and recognize symptoms of a disease. Furthermore, emotions influence perception of the signs and symptoms, that is, the severity of the state. All these aspects underpin the understanding and interpretation of signs as a threat or not. Furthermore, how one negotiates about the threat and care seeking is influenced by earlier care experiences. If they have been unsatisfactory, it seems that one prolongs the negotiation. Personal and social obligations also influence the negotiation as well as coping strategies, that is either avoidant or vigilant but also our self-efficacy.
Reminders may reinforce the intention to contact health care. Internal persuasion and acceptance finally lead to the patient to act upon the threat by seeking care. The further flow in the hourglass includes the management of people within the health care organization and depends on prioritization in health care and access to it. It also concerns sufficient information about methods of contact for patients. Communicative skills among staff, including gender awareness, sensitivity, and respect, influence the flow, as do competence, timing, and rapidity. Early and adequate primary excisions and referrals between clinics, and functioning teamwork in accordance with updated guidelines, are prerequisites for a sufficient flow. This may decrease the delay of diagnosis and treatment and thereby improve prognosis and decrease suffering among patients.
The negotiating process in decision making

The process from the discovery of a suspicious mark until people take a decision to seek care (I) is characterized as a time-consuming process of negotiation during which people are balancing between, on the one hand, deterrents from personal, social, and health care-related spheres, and on the other hand, an increasing threat. The increasing threat emerges from the interpretation of the suspicious mark and the potential disease it could develop into. As long as people do not get insights and therefore do not integrate the severity of the melanoma, the mark is not seen as a growing existential threat. The uncertainty about suspicions and the threat in itself needs to be confirmed or reinforced by some other before a final decision. As soon as people get insights into the seriousness of the mark, they make a quick decision and seek care immediately (I–II). The certain moment when the participants get insights and take a decision to seek care is a turning point; it could be described as a moment when the last puzzle piece is placed, and the whole picture of the situation becomes clearer. The insight about severity, or more precisely about an existential threat, is often initiated by others, such as partners, friends, children, grandchildren, or others. The experience of the existential threat touches the person, which leads to an increased understanding. The awareness about the existential threat is a motivation to seek care and a struggle for life (I). The negotiation in decision making about care seeking in MM is further interpreted according to the health belief model in Figure 4.

Figure 4. The health belief model (Rosenstock, 1974) applied on the decision-making process of care seeking in malignant melanoma.
The threat and the negotiation process, including barriers and benefits, self-eficacy, and coping are important parts of the decisional process, that is, how to act further, to seek care or not (I–III). As an example, people who with knowledge about MM who have detected typical signs, such as a very dark, new, colour-changed, bleeding mole, or skin changes that are not healing, become aware of the severe signs at an earlier stage and interpret them as symptoms of disease. Their environment and the people around them influence their perception and interpretation and thereby their decision (I–II). Messages such as others’ opinions, or alerts from media or significant others, could have great impact on their decision and experience of threat, but they also need a trust in themselves to know that they can do it and that the action could help them and facilitate dealing with the threat (I–II). Not every person needs all these prompts to make a decision to seek care when detecting life-threatening symptoms; it depends on the person’s own resources, such as knowledge, experience, awareness, personality, gender, coping styles as well as living conditions (I–III). In the same way, those who do not see the skin change as a possible cancer and do not relate to themselves as people at risk do not act fast; instead, they take time before they become aware of the threatening disease (I–II).

**Patient-related reasons for delay**

Deterrents in people’s personal spheres concerned experiences of uncertainty about the disease, feelings of being healthy, and viewing the change as something normal. The awareness among the participants about MM varied from a strong perception that it could be a very aggressive cancer to only viewing MM as something a physician easily could excide. Not wanting to burden the loaded health care system by seeking care unnecessarily was expressed as a deterrent. Despite the fact that many of the participants in our studies (I–II) expressed having a high knowledge about MM and that they often knew someone who had had MM, many participants did not reflect about being afflicted with MM themselves. They did not see or relate to themselves as being in the risk groups (I–II). There were also deterrents in the personal sphere relating to experiences with the health care system and earlier contacts, where previous negative experiences, and particular inaccessibility, complicated the care seeking process (I). Social deterrents, such as not having time to visit a physician or being too busy with work, prevented people from seeking care. Viewing care seeking as competing with other activities and responsibilities was also a deterrent, which contributed to the outdrawn process. Having family responsibilities and prioritizing others before oneself was another deterrent. Work was
described as being prioritized before care seeking, especially if the work involved other people, as is the case for health care professionals and teachers (I–II).

**Gender aspects delaying care seeking**

People decided in various ways to seek care, and many ways were similar between women and men. Other ways were different, and these were interpreted as being related to gender (II). The following five areas (in italics) of decision making to seek care, influenced by gender, were identified. **Attentiveness to bodily changes** concerned the importance of inspections of the body and bodily changes in relation to health. The focus on bodily changes was described in various ways. Expressing it as a way to maintain health was common among women. Men, who commonly did not focus on bodily changes, explained it as not looking for problems in advance. **Dependence in decision making**, that is, reliance on others, was commonly expressed among men, while women tried to convince themselves before decision-making. Information seeking, such as seeking for facts about the disease, was expressed by men as being more frequent among women, due to women’s worries about diseases. Therefore, men had a reason to rely on women’s competence about diseases and risks. **Emotional adaptation** after discovery of a mark dealt with various ways of expressing emotional engagement. Avoiding emotions and instead seeking care quickly was expressed and perceived as a cognitive and good solution among men, while women took time for emotional struggling and negotiation of competing needs before seeking care. **Self-management strategies** concerned actions taken after the discovery of the suspicious mark. Seeking care directly for an expert’s assessment, without wasting time on emotions and doubts, was commonly expressed among men. Trying to do something for themselves before unnecessarily bothering health care providers was a common pattern among women to self-manage the disease. ** Attribution of delay to responsibilities** was expressed differently among men and women. Attributing delay to work responsibilities was common among men, and attributing it to family responsibilities common among women. This difference in attribution related to attitudes of one’s own importance in the context, that is, women expressed that their needs did not exceed the needs of the family, while men emphasized their own importance at work (II).
Coping strategies in decision making

Different patterns in the decision-making process in care seeking imply a variation in use of coping styles influencing this process. The result in study III demonstrated that both men and women used less adaptive coping styles, such as buck-passing, procrastination, and hypervigilance, but men scored higher in buck-passing, while women scored higher in hypervigilance. In other words, men used avoidant coping strategies, implying the use of selective attention and distorted information processing or shifting responsibility; women tried to explore different solutions under a high level of stress, leading to a hastily made choice as solution. Participants living without a partner also scored higher in hypervigilance than those living with a partner. Age also influenced coping styles. People older than 72 years scored higher in both vigilance and hypervigilance. People with thicker tumours, regardless of gender, age, and living conditions, did not use different coping strategies than those with thinner tumours (III). People with nodular melanoma (NM), which is more rapidly growing and aggressive, scored higher on vigilance than people with MM in situ. The NM participants, though, were older and consisted of a smaller part of the total sample. No differences in coping strategies were found between those with SSM and NM (III). This indicates that the intensity of symptoms could be important for the interpretation and further process of negotiation and decision making to seek care. People might act by using more vigilance in cases of NM, because it produces more symptoms interpreted as severe and alarming. Vigilance as a coping strategy in decision making when people seek and process information thoroughly might be important for adequate preventive action.

Health care delay in Västerbotten

The clinical pathways and referral channels from patients’ initial contact to diagnosis, treatment, and follow-up are one means to describe the health care delay for patients with MM (IV). The largest proportion of patients (75%, n=53) had initially sought care and was primarily treated for suspected MM in Västerbotten County at the primary health care centres (PHC). The remaining patients sought care at other clinics, (Derm), that is, the public dermatological hospital clinic (15.4%, n=11), other hospital clinics (5.6%, n=4), and lastly, private skin clinics (4%, n=3).

Time from initial contact to the first assessment did not differ between PHCs and specialist clinics. Most patients seeking care at PHCs were excided there, before further referrals to specialist clinics. Ten percent of all patients
underwent a biopsy before the primary excision, which might have delayed the diagnosis process. Significant differences were found between the PHC and Derm groups in time interval (delay) from primary excision to the registration of results of the histopathological assessment (40.6 days vs. 22.4 days, \( p = 0.001 \)) (IV). People older than 60 years waited significantly longer from the first histopathological assessment to wide excision than younger people (41.1 days vs. 27.5 days, \( p = 0.005 \)), and also from referral for wide excision to wide excision (30.5 days vs. 22.1 days, \( p = 0.046 \)). People with thicker melanoma (>0.70 mm) waited significantly longer to be referred for follow-up than those with thinner MM (31.6 days vs. 17.4 days, \( p = 0.001 \)). Women waited a shorter time from the first assessment to the primary excision compared with men (40.8 days vs. 51.9 days, \( p = 0.052 \)), and also waited a shorter time from referral to wide excision (22.1 days vs. 30.9 days, \( p = 0.036 \)).
Discussion

Summary

As a summary of the results from this thesis, I first conclude that there were various reasons for patient delay. People either did not immediately understand how serious the suspicious mark was or did not experience any susceptibility to be affected by MM, and therefore delayed care seeking. Reasons from personal, social, and health care-related spheres influenced their delay and experience of threat, which further influenced their negotiation during the decision making process to seek care (I). Second, the decisional process of care seeking was also influenced by gender, whereby men and women used similar but also some different patterns in care seeking. Men relied on relatives’ advice and sought care without expressing struggling with emotions, while women detected suspicious marks by themselves, tried self-care remedies, and struggled with emotions before finally seeking care (II). Third, coping patterns in decision making were different between men and women and among those living without a partner and those not. Women and those living without a partner scored higher on hypervigilance, while men scored higher on buck-passing (III). Fourth, there were some differences in delay of diagnosis, depending on where people initially had sought care, and on their age and their sex. People seeking care at PHCs, older people, and men waited longer for diagnosis and treatment (IV). These results are further discussed in relation to other literature.

Patient and health care delay

Patient delay is well described in the literature and is implicated in the delay of diagnosis of MM. Participants in this study described different reasons for delay, wherein several reasons interacted and gave an additional effect. Perceptions of a lesion as normal and low discomfort from the lesion were understood as not alarming, or indicating a less serious symptom. Such perceptions and understandings led to a feeling of low threat and thereby low time pressure (I–II). When people perceived symptoms as vague, they were uncertain; because they could not persuade themselves about the threat, they await to seek care (I–II). People first sought care on their own when they got insight into the seriousness of the illness (I–III). These findings dealt with perception and recognition of symptoms, which has earlier been described in delay of care seeking for various other forms of cancer (Smith et al., 2005). In a synthesis of qualitative research on delayed care seeking in cancer, Smith et al. (2005) described how recognition of
abnormalities led to attribution of body changes to illness, to assessment of the seriousness of own conditions, and lastly influenced care seeking. This is in line with the results presented in this thesis. Long duration of symptoms, symptoms not disappearing, and symptoms worsening, or developing of new symptoms, were attributed to illness and influenced care seeking (Johansson, Wilson, Brunton, Tishelman, & Molassiotis, 2010; Smith et al., 2005). Seibaek et al. (2011) found that delayed care seeking related to vaguely interpreted symptoms among women with ovarian cancer.

Detection and awareness of MM are important, but not important enough to initiate care seeking. In this thesis people expressed how, from the discovery of suspicious mark to the decision to seek care, they used different strategies, avoidant as well as adaptive, to gain some control over the threat to life (I–III). If the symptoms had occurred suddenly and were more cancer specific, like a lump, or more serious, such as bleeding and not healing, people more easily understood or attributed it to serious illness and decided to seek care earlier (I–II). Faster symptom recognition and serious illness attribution are common among patients with more serious and specific symptoms (O’Mahony & Hegarty, 2009b; Smith et al., 2005). People with lung cancer did not seek care for their first symptoms, but they sought care faster, if they had more severe symptoms, such as haemoptysis or neurological symptoms (Lövgren et al., 2008). Concluded, recognition and interpretation of symptoms are vital to decrease delay but may not lead to care seeking (Seibaek et al., 2011; Smith et al., 2005).

There are also other prominent reasons for delay. Accessibility of health care, as well as the interaction and communication with health care professionals and also their competences, are crucial for timely diagnosis (I–II, IV). Participants in this study talked about the complexity of accessing the health care service and uncertainty about where to seek care for suspicious marks (I–II). Besides that, experiences of health care receptions as unprofessional and negative, and of not being prioritized as a patient (I), with a resulting long wait time, influenced patient, and also health care, delay (IV). Not having easily available information about where to seek care or where to refer patients might contribute to delay. To our knowledge, it is common that patients have been referred to various clinics without practitioners checking the guidelines as to where to refer them (IV), which often required additional referrals to the correct clinics, thereby causing delay. Similar organizational factors, such as delayed registration of results from histopathological assessments, which may delay diagnoses, were found in our study (IV).
Overload of work and tightened organizations may contribute to delay. The last report from the National Board of Health and Welfare (2011c) about waiting times in cancer care showed that there are differences between regions in Sweden, depending on tumour types and age groups. Also reported were unsatisfactory waiting times and lower accessibility within primary health care (National Board of Health and Welfare, 2011b). Difficulties in accessing health care, particularly primary health care, are in the literature described as reasons for delay among people with other forms of cancer (Byrne, 2008; Koyi, Hillerdal, & Brandén, 2002; Lövgren et al., 2008; Molassiotis, Wilson, Brunton, & Chandler, 2010). The organization of primary health care as a gatekeeping system can contribute to delay (Andersen et al., 2011). Studies have showed that time to referral for cancer was increased among patients who consulted GPs frequently (Goff, Mandel, Muntz, & Melancon, 2000; Mitchell et al., 2007). With increasing numbers of visits in health care (National Board of Health and Welfare 2011b, 2011c) and a situation where many people have possible cancer symptoms, it is essential that guidelines for treatment are evident, and used effectively. Effective use of guidelines and better access to diagnostic services has been called for in cancer care internationally (Macleod et al., 2009). Health care delay is sometimes caused by difficulties in diagnostics (Blum et al., 2007; Lindelöf, Hedblad, & Ringborg, 2008). If a symptom is more dramatic, such as pain and bleeding, the delay most often is shorter (Lövgren et al., 2008; Macdonald et al., 2006) than for less obviously significant symptoms. Symptoms such as bleeding can, though, also be misinterpreted as normal and thereby delay the diagnosis, for example, in colorectal and ovarian cancer (Fitch, Deane, Howell, & Gray, 2002; Mitchell et al., 2007). Time is central in delay, and particularly in MM, since the prognosis is related to early diagnosis. However, perception of delay and thereby perception of time may not be the same issues, especially when people feel healthy or do not experience a threat to their health (I–II).

**Objective clock time versus subjective time**

Through experiencing time people make sense of what and how illness influences them (Charmaz, 1993). Time is not only an objective experience, and the subjective experience of time has a great impact in people’s lives. Our findings, that people sought care when they really experienced an existential threat, can be understood as a new way of experiencing time. To become a symptom, a sign must be experienced and interpreted as a symptom related to ill health (I–II), which is also related to a person’s individual and cultural experiences (Ekman, Cleland, Andersson, & Swedberg, 2005; Tishelman, Taube, & Sachs, 1991). A threat is connected to an insight that illness is a disruption of the lived body, which is a way of
being in the world (Toombs, 1993). Such a threat’s influence on oneself is of importance for our perception of time (I). Symptoms of illness, illness experiences, and perception of time interact with each other (Charmaz, 1993; Groot, Derksen, Cru, Grol, & Vernooij-Dassen, 2007; Toombs, 1993). Illness or symptom perception and recognition are connected and crucial prerequisites for self-care actions, and if they do not connect, an expected self-care activity may not occur (I–II). According to Husserl (1964, 1989) there is a difference between objectivity and subjectivity and their influences on our consciousness. Lived time is an ongoing immediate experience, while objective time is measurable by clocks and calendars, and these cannot be compared. In these studies, many patients expressed that they had had signs about MM for a quite long time, but they did not seek care, because they did not ‘understand’ or had not experienced it as something serious or threatening, and thereby the signs did not influence or disrupt their lives (I–II). Hay (2008) also found that the subjective time perception of duration of signs is important for interpretation of sign intensity, and thereby, judgement of its seriousness. Sign intensity and duration are related to experiences of disruption in life and influence ones’ identity and time perception (McCann, Illingworth, Wengström, Hubbard, & Kearney, 2010). The deviation or disruption from ongoing, everyday life is a subjective experience of time, while objective clock time flows in parallel (Hay, 2008). The subjective experience of life, and thereby time, was not disrupted among many of our participants (I–II); therefore, they managed the sign of the mark according to this experience, with expectancy. Henly et al. (2003) described perceived time as an elastic continuum with potential to stretch or retract in relation to clock time, and parallel, ongoing to the clock time and biological/social time (Henly et al., 2003). Many of our patients described specific moments when something happened that influenced them to seek care. Those moments, or turning points, are the special experiences when people get an insight that the threat is really going to disrupt the everyday continuum (I). Turning points as the starting point for changed action in lives have earlier been described in the management of other chronic illnesses (Audulv, Norbergh, Asplund, & Hörnsten, 2009; Hörnsten, Jutterström, Audulv, & Lundman, 2011; Jutterström, Isaksson, Sandström, & Hörnsten, 2012). These objective versus subjective perspectives on time concern health care organization, health care workers, and patients with relatives. The organization, with its structured clock time for care, is often in collision with patients’ perceptions and needs of time, since they have different bases. Patients’ experiences of too little time to interact and reflect together with professionals (I–II), and extended waiting times for visits, are examples of collisions between subjective and objective time perceptions. Signalling lack of time in health care may imply lack of respect for patients’ embodied or lived time, which also is the result of the collision between
subjective and objective time (I). These experiences have previously been described among patients with lung cancer (Lövgren, Hamberg, & Tishelman, 2010). Insights into these different perspectives on time can help health professionals to understand why people do not act when an action seems obvious and expected, and why they delay.

**Patient-related reasons for delay**

Patients’ reasons for delay concern different aspects of their lives. Most people in our studies thought that the mark was a usual benign mole, which people normally have. They often did not see any change and had no discomfort from it. Low awareness of bodily changes as MM symptoms influences people’s negotiation about care seeking, especially if they feel healthy and live a normal life without any restrictions or discomfort and perceive the lesion as normal (I–II). Absence of pain, discomfort, and disturbance in life was expressed as a central reason for their delay (I–II). In the literature, vague symptoms are found to influence delay (de Nooijer et al., 2001a; Macleod et al., 2009). In contrast, alarming symptoms such as bleeding or pain, or experiencing a lumpy/raised change, are found to be a catalyst to act, and are described also in other forms of cancer (Geller et al., 2009; Leveälahti, Tishelman, & Öhlén, 2007; Macleod et al., 2009; Smith et al., 2005).

Beside vague symptoms, other competing activities in people’s lives delayed care seeking. Our participants described activities or responsibilities that consumed all their time and also their attention (I–II). This could be interpreted as a coping strategy to control life, but also as lack of awareness about MM. Not having time in life for management of a disease is described as delaying integration of chronic illness, where continually shifting perspectives on illness occur, that is, wellness in the foreground or illness in the foreground. In order to get control over life people may act to preserve wellness in the foreground of life (Paterson, 2001). Prompting by significant others was sometimes necessary for our participants to seek care (I–II). Relatives were important, both for detection and for speeding up decision making to seek care (I–II), particularly among men (II). People’s uncertainty about when signs become significant becomes evident when significant others must legitimate symptoms as impacting their being in the world (Hay, 2008; Jurgens, 2006; Patel, Shafazand, Schaufelberger, & Ekman, 2007). Participants also delayed care seeking since they did not want to burden the health care system and be judged as time wasters (I). This phenomenon is also described and interpreted by others as fear of embarrassment (Bish, Ramirez, Burgess, & Hunter, 2005; Macleod et al., 2009; Mitchell et al.,
2007; Smith et al., 2005). Furthermore, earlier negative experiences of the health care service, such as inaccessibility; unkind and unprofessional reception; and time-consuming, complicated, and unclear pathways to reach health care (I, II), were of certain importance for delayed diagnosis and treatment (IV). Negative care experiences are also reported to be a reason for not seeking care (Byrne, 2008; Patel et al., 2007) and not attending screening for cancer such as cervical cancer (Blomberg et al., 2008). There is a risk that dissatisfied people do not seek care again, and thereby prognosis will be worsened (Lilliehorn, Hamberg, Kero, & Salander, 2010; Molassiotis et al., 2010). Smith et al. (2005) also described that such experiences can lead to delay.

**Fear and threat are necessary for care seeking**

Emotions arise during the process of detection and interpretation of a suspicious mark and influence further action (I–II). Feelings such as fear and threat influence coping strategies (I–III). Among our participants, fear was expressed as being connected to stress and an insight into need for further action—care seeking (I–II). In the literature, fear and threat have been described as resulting in defence and avoidance, and thereby delayed care seeking (Ruiter et al., 2003; Temoshok, DiClemente, Sweet, Blois, & Sagebiel, 1984). In a review about patients’ help seeking for cancer, Smith et al. (2005) declared that fear as reason for delay is often expressed as fear of embarrassment or as fear of cancer. According to Rogers’s protection motivation theory (PMT) (Rogers, 1983), perceived threat includes perceived susceptibility and perceived severity. According to PMT, a sufficiently high threat and also a high self-efficacy will lead to engagement in appropriate health behaviour; if one or both are insufficient, people will not engage. Witte (1992) suggested in her extended parallel process model that these two appraisals, threat and self-efficacy, will result in either engagement in an ‘adaptive’ response (i.e. appropriate actions to reduce a danger) or in a ‘maladaptive’ behaviour (taking no action; using a range of other coping strategies to reduce the fear, but not the danger). De Nooijer et al. (2001b) also found that fear could be either an initiator or inhibitor of care-seeking behaviour. However, moderate levels of threat are suggested to be most effective and initiating (Janis & Mann, 1977), which is in line with our findings (I–III). Zola (1973) also found that fear and stress were reasons that brought people to hospitals or triggered their care seeking. My own interpretation from the findings (I–II) is that people who fear cancer will seek care, if they really have understood and convinced themselves about the seriousness of their symptoms. Such convincing is based on a complex emotional and cognitive reasoning, leading to interpretation of the symptoms and the threat (I–II). As Hay (2008) found, serious and
disruptive signs coupled with longer duration became symptoms, when they impaired one's ability to manage daily activities. When threat is established, the benefits and costs are balanced against the perceived impact of symptoms on quality of life (Shaw, Brittain, Tansey, & Williams, 2008). My conclusion is that fear is needed if people are going to act on symptoms of MM, but those who seek care use both cognitive and emotional strategies, that is, knowledge and fear—an active coping strategy—to seek care (I–II). From the literature we know that fear can be a catalyst of care seeking, but can also lead to delay (Ackerson & Preston, 2009; Mitchell et al., 2007; O'Mahony & Hargarthy, 2009a; Smith et al., 2005). De Nooijer et al. (2001a) found two groups among those who felt fear, those who were anxious by nature and those who were aware of and feared cancer. Some people did not seek care, because they feared the confirmation of their own suspicions. On the other hand, those who did not feel any fear also delayed care seeking. Those who do not seek care due to fear, according to de Nooijer et al. (2001a), need information about cancer but they also need to know that delay can lead to more fear.

Not expressing fear may be an effective coping strategy to reduce overwhelming feelings, but also a maladaptive behaviour in MM (I–II). Strong fear, though, has been correlated in the literature with uncertainty, avoidance, and risk aversion (Lerner & Keltner, 2000, 2001); however, we found that fear and threat as well as increased knowledge about the severity of MM forced people to seek care (I–II), which is in line with Ackerson and Preston (2009), who report that adherence to cancer screening is achieved when people fear cancer, understand the severity, and seek knowledge, and also when they trust care providers. This indicates that fear is correlated to other features and strategies among people, such as knowledge and awareness. A meta-analysis reviewing fear provides strong support for the assumption that higher levels of threat and higher levels of self-efficacy result in greater changes in attitude, intention, and behaviour (Witte & Allen, 2000). Controversially, in a later study, Ruiter et al. (2003) found that threat was related to fear appraisal, but not significantly positively related to coping (danger control), which indicates that coping is more influenced by trust in the effectiveness and feasibility of recommended actions. Consequently, according to Ruiter et al. (2003), preventive information with threatening content should be used carefully. On the other hand, such information has been reported as being effective. Messages stressing losses have been reported to be more effective in promoting active skin cancer detection by skin self-examination, but only among persons with high self-efficacy (van't Riet, Ruiter, Werrij, & De Vries, 2010). Ruiter et al. (2008) also found that threat led to adaptive coping, if people had actively detected and recognized symptoms. In summary, knowledge and awareness about symptoms improve
detection; they interplay with experiences of threat and coping and thereby also with the decisional process.

My conclusion is that a moderate level of fear is needed, since it influences the experience of symptoms, and also further actions, where those who are really aware of cancer and worried for the future might seek care in a higher degree (I–II). Fear and anxiety have been shown as leading to decreased delay in myocardial infarction (Morgan, 2005) and breast cancer (O’Mahony & Hegarty, 2009b). In a review of impact of fear on patient delay, Duabyova et al. (2010) state that a high level of fear was associated with earlier help-seeking among those with cancer symptoms and myocardial infarction. The relation of anxiety and worry to appraisal of symptoms has been investigated by others (Ristvedt & Trinkaus, 2005), who found that people with low level of anxiety needed more time for symptom appraisal and scored health higher, but more seldom sought care or participated in screening. Men participating in studies of this thesis described that they seldom expressed fear and emotional struggles before diagnosis and instead used avoidant coping strategies (II–III).

**Gender patterns in care seeking influence delay**

Women and men expressed somewhat different decision-making processes in care seeking, which could be gender influenced. Men expressed that they did not pay attention to bodily changes, relied on their wives’ advice, and sought experts’ help without giving space for emotions. Women expressed that they relied on their own ability to seek information and act, expressed emotional issues, and then sought care (II). In the literature, differences in incidences of various diseases, but also differences in health behaviour, are described between sexes. Women are reported to be more prone to participate in screening for MM (Sach & Whynes, 2009; Youl et al., 2006) and to more often describe their feelings than men do (Schofield, Connell, Walker, Wood, & Butland, 2000). On the other hand, men are reported as reluctant to seek care (Addis & Mahalik, 2003). Many studies have used a biological perspective on sex to describe differences between men and women, which makes it difficult to draw conclusions about gender differences in care seeking. Also, bodies are socially structured, since our interpretation and views of them are influenced by society (Connell, 2003). To understand and interpret such differences, I have used a gender constructive perspective, since it influences our communication, our expressions based on the expectations on women and men.
Having a high attention to bodily changes, worry for illness, and emotional engagement among women (I–II) fits well with a feminine stereotypic gender construction, while not seeking care, and thereby avoiding the appearance of weakness and being stamped as a hypochondriac, fits well with a masculine stereotypic gender construction (cf. Nikolajeva, 2004). The patterns in care seeking of the participating men and women in this thesis (I–II) fit well with such stereotypic gender constructions, as well as their coping strategies in decision making (III). Women described to a greater extent that they themselves discovered the marks on their bodies, sought information, and knew much about MM (II). Others have also found that women self-detect melanoma to a greater extent than men (Betti et al., 2003; Blum et al., 2007; Carli et al., 2004) and are more aware of bodily changes and the importance of self-examination (Swetter et al., 2009b). Men in our studies also reported that they knew that women paid more attention to bodies and diseases, which was a major reason for men to rely on women (II). These findings were interpreted as gender influenced and related to the dominating masculinity norms in western societies, which influence their care seeking (Courtenay, 2000). Men and women seem to act differently with respect to attention to bodily changes, something that may be a result learned from society, as a norm and ideology regarding what it means to be men and women (Addis & Mahalik, 2003; Galdas et al., 2010). The norm of masculinity also fits well with our finding that men prioritize work more that health behaviour (II), since they are expected to be strong. For women the feminine norm may influence them to view their family responsibilities as having higher priority (II). Other studies have also reported that women delay care seeking for cancer, because they prioritize family responsibilities over their own health (Smith et al., 2005).

While masculinity entails being strong, firm, protective, and active, femininity entails being worried, dependent, pleasant, thoughtful, and accommodating (Nikolajeva, 2004). Women in our studies (I–II) also wanted to try self-care and become more sure about the symptoms before seeking care, something we have interpreted as a response related to the norm of femininity as taking responsibility for bodily problems. From the literature we know that women seek care earlier, and their prognosis is better in malignant melanoma (Scoggins et al., 2006; Swetter et al., 2009b). A masculine gender construction may delay care seeking, since it implies not being observant of bodily changes (Connell, 1995; Nikolajeva, 2004). Galdas et al. (2005) also state that ‘traditional masculine behaviour’ can explain delays in men’s care seeking. Schofield (2000) reported that men more likely focused on physical problems than disclosure of mental and emotional problems. Similarly, McCaughan and McKenna (2007) described how men with cancer avoided dealing with psychological needs by wishing to go back
to ‘normal’ life and work, and less often sought information about illness. They experienced discomfort in health care settings, but relied on partners as information gatherers. Our own attitudes as health care professionals can also influence our expectations of men’s and women’s care seeking, and thereby also affect their care seeking patterns and experiences of care (Seymour-Smith, Wetherell, & Phoenix, 2002). Health professionals’ interpretation of patients’ symptoms is another issue that may be gendered, since gender as a social construction interplays with symptom interpretation and thereby influences delay (Galdas et al., 2010; Martin & Lemos, 2002). Gender as a socially constructed dimension in relation to care seeking is an important topic for further study, since both women and men delay, but in somewhat different ways. Women might detect their marks earlier, but need time to become convinced. Men more often neglect bodily changes as a mark for a period of time and need someone else to detect the new or changed mark and persuade them to seek care, but then they seek expert help immediately (II). In concordance with Hunt, Adamson, and Galdas (2010) and Galdas (2010), I agree that more gender-comparative research is needed in order to understand the care-seeking behaviour, that is, the seeking care patterns that are similar and different among men and women. Gender patterns influence decision-making processes in care-seeking behaviour, which implicitly means also that coping as part of the decisional process is influenced by gender.

Coping in decision making varies between men and women

During such a stressful circumstance as experiencing a mark that may be life-threatening, coping strategies are crucial to handle stress and to make the right decision. Coping strategies are, though, influenced by many other factors, such as earlier experiences of stressful events and their impact on oneself, the kinds of these various events, and also the age and gender of the person (Helgeson, 2011). Experiences of stress levels can vary between men and women, depending on the kinds of events. Men and women are also differently represented in different kinds of traumatic events, for example, war trauma or sexual violence. Results in study III showed some differences in decisional coping styles among people with MM, where women reported more hypervigilant coping strategies, and men reported more use of buck-passing strategies. The hypervigilant style is often described as related to high levels of stress and panic actions, but in relation to our studies, it is suggested that hypervigilance be interpreted as positive and effective, since it may decrease delay of care seeking (II–III). Women’s higher attention to bodily changes and emotional struggles found in study II could also be interpreted as an expression of their worry about health. Buck-passing is a sort of avoidance in which people use selective attention or distorted
information, or shift responsibilities. Previous studies among younger people have reported that girls experience more intrapersonal stress than boys, which can influence their coping (Hampel & Petermann, 2006; Murberg & Bru, 2004). MacSwain et al. (2009) found that, among many similarities in men’s and women’s coping strategies, women had a higher level of reassurance-seeking and more worry than men, which included worry about health issues. These differences in coping between men and women are often explained by the different engagement in coping, whereby women more often than men tend to engage in several coping strategies and more often use a flexible approach to stress, so-called tend and befriend, as opposed to fight or flight (Helgeson, 2011).

Women are also described as more strongly affected by stressors that involve others, while men are more strongly affected by work and financial stressors. A hypervigilant style, including a need to talk, seek information, and ruminate about a threat could be interpreted as a more women-specific coping style. Wengström et al (2001) also found that family and social networks had positive impact on coping processes among women with breast cancer. Such strategies as positive self-talk (encouraging oneself), seeking support, and rumination, were found by Tamres et al. (2002) as the largest sex differences in coping between men and women, and these strategies were more utilized by women than men. When experiencing health threats, women were found to make greater use of social networks, considered important for decreasing patient delay (Pedersen, Olesen, Hansen, Zachariae, & Vedsted, 2011). Tamres et al. (2002) also found that, although women engaged more in coping than men, men engaged in relatively more active coping strategies and distraction, while women engaged in relatively more support-seeking strategies. This could be compared to our result, where men scored higher on buck-passing and women on hypervigilance (III). On the other hand, our results from qualitative studies showed that men were more active when they were told to seek care than were women, who struggled with emotions and need for support, since they might be more affected by stressors involving others (I–II).

Men also sought help after advice, but they preferred to get expert help, while women tried to do something and negotiated longer in order to accommodate themselves to the situation (II). These findings could be related to the impact of control in coping. According to Helgesson (2011), it is suggested that women use more secondary control strategies than men. Primary control strategies are strategies that alter the environment, while secondary control strategies are control strategies that alter the self to accommodate to the environment. A study from 2007 (Chipperfield, Perry, Bailis, Ruthig, & Loring) showed that use of primary control strategies was
low among women in situations of acute health events, while men continued to use primary control strategies, regardless of whether they had experienced an acute health event or not. Concluded use of various coping strategies to handle a life-threatening situation is important and can vary between men and women. However, such differences are complex and difficult to generalize about, since there are many factors influencing them, such as the context, experience, personality, and age, and also the gender and status of the persons (Emslie & Hunt, 2008; Helgeson, 2011), though not included in my analysis.

**Health care delay varies between clinics, gender, and ages**

The most common places where people diagnosed with MM had sought care were the primary health care centres, which was expected (IV). People diagnosed with MM are most often over 60 years and may not make contact with referral-free clinics to the extent that younger people do, since older people do not often seek information about these clinics on the Internet to the same extent as younger people (Selg & Findahl, 2008; Soederberg Miller & Bell, 2012). It is also more common that older people also have other diseases (Marengoni et al., 2011; van den Akker, Buntinx, Metsemakers, Roos, & Knottnerus, 1998), and therefore more often seek care at the PHC (Kadam & Croft, 2007), which can influence their decisions about where to seek care for a suspicious mark. Another factor in seeking care at a PHC is the shorter distance to a PHC, and the lower costs, but also the fact that patients often need a referral to visit a specialist. Many participants said that they did not know about the referral-free clinics, but they also talked about the lack of clear information about where to seek care, which did not facilitate their decision (I–II). The absence of private skin clinics in rural areas may also influence the choice of clinic for initial contact. However, since thicker melanoma is more common among older people (Tsai et al., 2010), thicker melanoma was more common among people seeking care at PHCs. The findings that people seeking care for suspicious moles at PHCs waited longer for the registered histopathological results than those seeking care at the dermatological clinics (40.6 days vs. 22.4 days; \( p = 0.001 \)) was dissatisfying, since we know that thicker tumours are related to worse prognosis (IV). I have no explanation for the extended time for registration of the histopathological results. However, health-care related contribution to delay of diagnosis is not compatible with quality MM care. Factors such as high workload, gatekeeping, and increased visits within PHCs, as well as decreased visits and accessibility within specialist care (National Board of Health and Welfare, 2011b) and an increased ageing population (SCB, 2011), might contribute to such an outcome. There are differences in MM
distribution and survival between men and women (Joosse et al., 2010; Scoggins et al., 2006), but also in relation to age (Lasithiotakis, 2008; Lasithiotakis et al., 2010). Women in our findings waited a shorter time than men (IV). Since women more often have thinner melanoma and discover the marks by themselves more often than men do, and thereby seek care earlier (Baumert et al., 2007; Carli et al., 2004), it is vital that health care professionals seize the moment when a possibility of early detection of MM among men is presented, for example, when they seek care for other health problems.

Geller et al. (2009) found that physicians often discovered MM in elderly people with a tumour thickness lower than self-detected melanoma or melanoma detected by others. This indicate that physicians, and also nurses, when examining patients’ bodies, have a great opportunity to detect and diagnose MM earlier (Tsai et al., 2010), which should lead to better prognosis. A shorter waiting time (health care delay) (IV) could be related to the thinner MM among women, but also their care seeking patterns and higher extent of self-detection (Carli et al., 2004; Schwartz et al., 2002; Swetter et al., 2009b; Tsai et al., 2010), and of course, also the beneficially biological features of MM among women (Geller et al., 2009; Spatz, Stock, Batist, & van Kempen, 2010). It is, though, possible that other aspects, such as women’s hypervigilant coping (III) and higher worry or anxiety (MacSwain et al., 2009), also contribute to earlier care seeking.

Among our participants, older patients waited for wide excision nearly twice as long as younger patients (IV). According to evidence from a review (Tsai et al., 2010), the elderly over 60 years of age were more likely to be inadequately surgically treated. This is contradictory, since elderly patients more often have thicker melanoma, and older age is reported to be an adverse prognostic factor for melanoma patients (Balch, 2001; MacKie et al., 2009; Tsai et al., 2010). In a study regarding treatment of lung cancer, Lövgren et al. (2008) also found that the older patients waited longer for start of treatment. A problem with aging is that multimorbidity might become a hindrance for treatment, since it is related to other risks and prognoses and leads to more extensive management and longer waiting, which is common also in other forms of cancer (National Board of Health and Welfare, 2011b). Studies from England of other forms of cancer have shown that both age and gender can influence people’s decision-making process regarding treatment, where older people and men more often were perceived as passive, while younger and well-educated people and women took a more active participatory role (Deber, Kraetschmer, Urowitz, & Sharpe, 2007). According to Tariman et al. (2012), health care professionals’ perceptions and beliefs about patients’ life expectancy, likewise their
expertise and communication style, influence decision making regarding further treatment of cancer, which could be referred to our results of time delay in management of those older patients (IV). Time differences in management within health care depending on age and gender of the patients are also presented in other studies (Ryan & Sysko, 2007). The health care delay is a smaller part of total delay (Macleod et al., 2009), but critical, since these patients already have delayed themselves for a period of time. There are only a few studies that explore the health care delay in treatment of melanoma (Richard et al., 2000b; Schmid-Wendtner et al., 2002), particularly in Sweden (Hansen et al., 2011a; Hansen et al., 2011b; Olesen et al., 2009). Despite the fact that health care delay is the smaller part of the total delay, there are possibilities for improvement in MM care, that is, to diagnose and treat MM patients earlier (Ahnlide & Bjellerup, 2006; Murchie et al., 2011; Paoli, 2009; Richards, 2009; Wheeler, 2009). Besides practical tasks, such as organization and guidelines, aspects as communication, interaction, and reception of patients are important (I–II, IV) not only to raise awareness and to help people to seek care earlier for suspect marks but also to utilize the opportunities when people are seeking care for other diseases.

Conclusions

Detection of a suspicious mark is not sufficient to provoke further action. Some people delay, even if they have knowledge about MM or if they have detected suspicious marks. Experiencing fear can lead to both adaptive and less adaptive actions. When people experience threat in combination with other factors, such as prompting information, it is suggested that people delay care seeking for a shorter time. Knowledge, support, prompting, and reminders, both from significant others and from health care professionals, are necessary prerequisites for increased understanding of the seriousness and susceptibility of MM. It is suggested that negative experiences with health care contacts increase patient delay. Clear information about where to seek care and also a high accessibility of health care are necessary, if we want to get people to seek care earlier for suspected MM. Nurses and GPs in primary health care have a great opportunity to detect MM among people seeking care for other conditions. Because gender patterns also influence detection and care seeking for MM, men and women may act differently when deciding to contact health care. Health care delay of MM varies between clinics and depends on where people seek care initially, and on their age and sex. Improved and utilized communication, increased use of
guidelines, and also improved accessibility might decrease the delay of diagnosis.

Clinical implications

Since individuals use various decisional processes and cope in different ways, the public health system needs to adapt preventive education. Increasing people’s knowledge about early warning signs of melanoma is only one fundamental component of preventive educational programmes to detect MM earlier. Melanoma suspicious marks are not always easy to detect and suspect, particularly if vague symptoms or no discomfort are experienced. It is therefore important to further increase knowledge about early signs, to increase awareness. If patients and health care professionals could learn more about atypical, less known symptoms, such symptoms might become well known, and thereby greater possibilities would emerge to make people aware of them.

Information based on benefits with early care seeking and losses associated with MM, coupled with an emotionally touching message, is suggested as a method to trigger people’s actions. Some level of ‘threatening’ information used with caution may be effective, if balanced with a hopeful message that it is simple to cure MM if care is sought in time. Emotionally affecting information, concerning feelings about appearance and risks of sun exposure in relation to the possible existential losses if MM occurs, used in a way that gives people a possibility to identify themselves as susceptible could trigger a moderate level of stress and thereby preventive actions. Preventive information should be adapted and used in various ways employing different media in order to reach both the older and younger populations as well as men and women. The primary message in prevention would be simply to inform people that MM can affect everyone, and that is why it is important to be aware of bodily changes, examine one’s body, stay out of the sun or cover-up with clothes, and finally, when detecting suspicious skin changes, seek care immediately.

Nurses, particularly within primary health care, are involved in care of patients with suspected MM and can act as educators, supporters, and coordinators for these patients (Wheeler, 2009). The role of nurses in encouraging people to perform self-care is central in Orem’s self-care theory (Orem, Taylor, & Renpenning, 1991), which have been a frequently used nursing theory in primary health care nursing and can be further developed. Primary health care nurses can further use new technical tools to detect MM.
earlier, and also to better coordinate and speed up the management of patients with detected MM. A main future challenge in research is how to get people, and especially those who have knowledge but low reflection about susceptibility for MM, to seek care.
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