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**UNDERSTANDING DELAY: A GROUNDED  
THEORY EXAMINATION OF THE PRE-  
DIAGNOSTIC JOURNEY OF INDIVIDUALS  
WITH MALIGNANT MELANOMA**

An analysis of the experiences of individuals subsequently  
diagnosed with high  
risk malignant melanoma from problem identification through to  
initial specialist  
treatment

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Submitted for the degree of  
Doctor of Philosophy

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2008

## **ABSTRACT**

Malignant melanoma (MM) is a curable malignancy and survival prospects are associated with early detection and tumour thickness at time of diagnosis. When detected and treated early, melanomas usually have a favourable prognosis. Nevertheless a substantial number of individuals present for diagnosis with extensively invasive disease. There is limited evidence examining why presentation delay occurs - something this study sought to rectify.

The aim of the study was to explore the pre-diagnostic experiences of individuals diagnosed with MM, mapping their journey from problem awareness to diagnosis in order to illuminate the influences on delay. Qualitative conversational interviews with a purposive sample of individuals (n=36), diagnosed with MM were undertaken, complemented by a theoretical sample of individuals with superficial tumours (n=6) described as non-delayers at diagnosis. Interviews were audio-taped, transcribed and analysed using a Constructivist Grounded Theory Approach. Constant comparison underpinned data collection and analysis.

Two broad categories that accounted for delay and best conveyed the experiences of informants emerged from the study. The first category, accounts for the perceptions involved in interpreting symptoms. These include how individuals judged their risk of getting melanoma, how they interpreted their symptoms and how they understood illness and health. The second category identified other non physiological factors such as perceptions of life responsibilities and commitments, perceptions of masculinity and perceptions of medical services as also being factors in presentation delay.

This thesis presents an interpretation of the experiences of individuals who present late with MM and offers an understanding to inform effective health promotion and education.

### **KEY WORDS**

Malignant melanoma; Grounded Theory; Presentation delay; Help seeking; Diagnosis; Patient experience

## **DEDICATION**

This thesis is dedicated with all my love to Tatenda, dear Tatenda who endured many a disturbed nights sleep, who listened patiently to many a moan, who gave many a much needed hug, who cooked many a much needed meal, who kept me in the 'luxury to which I have become accustomed', who diligently proof read the thesis and not once did he complain.

## **ACKNOWLEDGEMENTS**

To Prof Annie Topping, my supervisor, (and woman extraordinaire) who inspired me, motivated me, guided me and kept me sane! I can not begin to express my thanks for all your hard work. Thank you for introducing me to the wonderful world of research.

To Jane my wonderful sister who has always been my greatest fan. Thank you for everything.

To Mumu and Fifi, my favourite little people, for always making me smile.

Ma and Prim-rose (aka Shukie) much love

My family-in-law for their support and prayers

All the staff in the Dermatology Outpatient Department especially Dr. Wright and Catherine without whom this project would not have been a success

Special thanks to all those who gave of their time, opened their homes and very often their hearts to me and shared their stories. Without you there would be no thesis.

Finally, to my Maker for enduring faith and hope that, though sometimes as dim as the embers of a dying fire, never died.

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## **INTRODUCTION**

Malignant melanoma (MM), the most life threatening form of skin cancer, currently accounts for about one in every 100 cancers (NHS Direct 2008). Once considered an uncommon disease, the annual incidence of melanoma has increased dramatically over the last few decades making it one of the fastest growing cancers today (Cancer Research UK 2007). Of all human malignancies MM is unusual because its onset and development can be detected visually (Brooks et al 2001). Despite this unique opportunity for curative treatment to be carried out as signs and symptoms can be recognised early, mortality rates across the world steadily continue to increase. However, despite these trends, melanoma is a curable malignancy and survival prospects are associated with early detection. If caught early, the prognosis for MM sufferers is excellent. Clearly this indicates that early presentation is significant in terms of outcome. Nevertheless a substantial number of individuals present for treatment with extensive invasion of disease on diagnosis. There is limited evidence examining why presentation delay occurs - something this study sought to rectify.

### **GENESIS OF THE RESEARCH PROJECT**

The impetus for this research project arose from my experiences of working as a dermatology staff nurse on rotation between a dermatology outpatient department, dermatology inpatient ward and plastic surgery ward. Here I had the opportunity to work with MM patients and witness first hand the full range of treatment options available to them. It soon became apparent that not all patients presenting with lesions for diagnosis and treatment were at the same point in the disease trajectory. Indeed, some lesions (that

were subsequently discovered to be MM) were thin and could be excised safely in the outpatient's department. Other lesions, however, were thicker and required much more intensive surgical intervention, a few requiring other modality treatments such as radiotherapy, often on an inpatient basis. For an unfortunate few, it was too late for the clinicians to offer any curative options and only palliative treatment could be offered. These scenarios concerned me and I found myself wondering why these patients had not come sooner. Informal discussions held with senior clinical and academic staff revealed that there were no ready answers to explain delayed presentation or what prompted people to present for diagnosis and treatment. This resulted in an extensive literature search being undertaken. The literature search strategy is described later in the thesis. What the literature search revealed was a dearth of information on the problem of presentation delay in MM. Furthermore, the literature search highlighted the growing incidence of MM and the need for more MM specific research to explore these issues.

This thesis represents a three and a half year investigation into MM presentation delay. The key question under investigation was:

**What are the challenges, if any, that individuals subsequently diagnosed with malignant melanoma face that impede or facilitate their presentation for diagnosis and treatment?**

I now present my contribution to understanding delay in MM patients.

## ORGANISATION OF THE THESIS

This thesis is divided into four major parts.

### **Part One: Background and literature**

Part one (chapter one to three) forms the foundation on which the thesis is built by giving a detailed overview of the issues around MM and what is currently known about presentation delay. Chapter one gives a summary of the science of MM including aetiology, statistics of incidence, its symptoms and available treatment options. In chapter two the key issue of pre-diagnostic delay in MM is discussed. The chapter begins by giving an overview of the concept of presentation delay, offering the definition of delay that will be used throughout the study and analysing a model of delay in the context of MM care. Considerable attention is also given to the results of an extensive literature review and the factors identified as being related to pre-diagnostic MM delay are discussed. To conclude the first part of the thesis chapter three considers the complexities of help seeking behaviour focusing on the study of illness behaviour.

Although the literature is presented in what appears to be a linear form, this was done in order to present the data in a logical, structured format and to facilitate understanding. In reality, the literature review evolved over the duration of the study. While the first two chapters were written at the beginning of the project, their content was modified over the duration of the project in order to accommodate emerging issues of interest. For example, although the original purpose of the second chapter was to discuss the key issues around presentation delay in MM and provide a working definition of delay, certain components of the chapter, such as the model of patient delay, were added later as their relevance

became apparent. The third chapter of the thesis on help seeking behaviour was written further along in the study when data collection and analysis had commenced and it became increasingly clear that the issues around help seeking behaviour (and especially illness behaviour) had to be considered in order to present a more complete and grounded study. Other literature subsequently presented in the thesis also evolved from an analysis of the emerging research data rather than from a defined linear process.

### **Part Two: Methodology and design**

Part two (chapter four and five) presents the research process undertaken and provides a rationale for the chosen methodology. Chapter four gives an outline of the study's philosophical approach and links the ontological and epistemological perspectives of the study with the chosen qualitative methodology; constructivist grounded theory. The chapter also introduces the idea of rigour and discusses how the quality of the various conclusions that are reached in the study will be appraised. Chapter five is the research design chapter of the thesis and gives a detailed account of the ethical and procedural aspects of the study, detailing the systematic and rigorous approach to enquiry used.

### **Part Three: Research Findings**

Part three (chapter six to eight) presents the research findings. Chapter six presents the findings related to symptom interpretation or, as is more often the case, symptom *mis*interpretation. Chapter seven explores the social aspects of delay and the role played by family, friends and significant others in presentation delay. The chapter also discusses the triggers for action that finally prompt the individual to act upon their symptoms. In

keeping with the grounded theory methodology two unexpected dimensions; support and survivorship, emerged from the study and these are presented in chapter eight of the thesis. All names presented in these chapters are pseudonyms in order to protect identities.

#### **Part Four: Discussions and Recommendations for Practice**

Part four (chapter nine and ten) are the final two chapters of the thesis and present an analysis of the research findings and a summary of the research endeavour. In an attempt to address the research question chapter nine presents the ‘portrait of a delayer’ which provides a thick description of the characteristics of individuals who delay and the challenges they encounter. Chapter ten focuses on how early detection in MM can be enhanced by identifying challenges that may be a barrier to early detection and how they can be overcome. The chapter also provides recommendations for clinical practice, further research and an outline of the study’s limitations. The thesis concludes with the author’s reflections on conducting the research project.



PART ONE

**BACKGROUND AND LITERATURE**

# 1. CHAPTER ONE

## THE SCIENCE OF MELANOMA

### 1.1 INTRODUCTION

This introductory chapter presents the context of the thesis by giving a detailed overview of MM beginning with its histology and aetiology. The second part of the chapter focuses on the incidence or occurrence of MM in the United Kingdom by age, sex, ethnicity as well as global epidemiological trends. Mortality and survival rates are also discussed. In the third and final part of the chapter clinical aspects of MM such as its symptoms, how it can be prevented and treatment options are considered.

### 1.2 HISTOLOGY

There are three main types of skin cancer; basal cell carcinoma (BCC), squamous cell carcinoma (SCC) and malignant melanoma. BCC and SCC are often grouped together and referred to as non-melanoma skin cancer.

#### 1.2.1 NON MELANOMA SKIN CANCER

Basal Cell Carcinoma (BCC), also called basal cell epithelioma or rodent ulcer is the least aggressive type of skin cancer and with more than 65 000 estimated cases in the UK alone annually (Cancer Research UK 2006) it is the most common malignancy in humans. This cancer develops from basal cells which line the deepest layer of the epidermis. An abnormal growth- a tumour- of this layer is what is referred to as BCC. It typically occurs in areas of chronic sun exposure such as the face, ears, neck, scalp and shoulders but can also develop on the back or lower legs. BCC is usually slow growing and very rarely

metasises although it can cause clinically significant local destruction and disfigurement if neglected or treated inadequately. It is not usually life threatening. Prognosis is excellent with proper therapy.

Squamous Cell Carcinoma (SCC) is the second most common form of skin cancer and constitutes of about 20% (1 in 5) of skin cancers diagnosed (Cancer Research UK 2006). This cancer begins in cells called keratinocytes, which are in the upper level of the epidermis. SCC most often develops in areas that have been exposed to the sun but can also develop in scars, areas of skin that have been burnt in the past and areas of skin that have been ulcerated for a long time. In a small number of cases, SCC can develop in the genital areas. (Skin Cancer Foundation 2006). In addition, chronic skin inflammation or medical conditions that suppress the immune system over an extended period of time may encourage development of SCC. SCC is more aggressive than BCC as it has a faster growth rate, less well-demarcated margins and greater metastatic potential (Preston and Stern 1992). While 96 to 97 percent of SCCs are localised, the same percentage (96 to 97 percent) of the remaining (3 to 4 percent) cases can spread to other parts of the body and the results are often fatal (Skin Cancer Foundation 2006). Due to very large numbers of cases each year, non-melanoma skin cancers constitute a substantial public health problem.

### 1.2.2 MALIGNANT MELANOMA

Malignant melanomas are the least common but most serious type of skin cancer, with 8,100 new cases each year in the UK and 1,800 deaths (Cancer Research UK 2006). Although MM can occur anywhere in the body, including in the internal organs, this thesis

only focuses on the experiences of those who have developed melanoma of the skin often referred to as 'cutaneous' malignant melanoma. There are four basic types of melanoma which differ in frequency and location on the body. At one time, the types were considered to carry different levels of danger. However, increased understanding of skin cancer indicates that one type of melanoma is not inherently more dangerous than another. They all pose the same level of danger, based on factors like the depth of the tumour, the presence or absence of ulceration, the number of regional lymph nodes containing melanoma and the extent of cancer spread in the regional lymph nodes (Melanoma Centre 2003).

#### Superficial Spreading

Superficial Spreading MM is the most common type of melanoma. About 7 out of 10 of all melanomas in the UK (70%) are this type. As its name suggests, it spreads along the epidermis for a period of months to years before penetrating more deeply into the skin. As illustrated by figure 1.1 the melanoma appears as a flat or barely raised lesion, often with irregular borders and variations in colour. Lesions most commonly appear on the trunks of men, the legs of women, and the upper back of both sexes. They are most common in middle aged people (Melanoma Centre 2003). The melanoma does not become dangerous until it begins to grow vertically into the deeper layers of skin and beyond. The earliest sign of a new superficial spreading melanoma is darkening in one part of a pre-existing mole or the appearance of a new mole on previously unaffected normal skin.



Figure 1.1 Superficial Spreading Malignant Melanoma

#### Nodular melanoma

Nodular melanoma is the most aggressive type of melanoma and accounts for about 25% (about 1 in 4 melanomas) of all melanomas diagnosed in the UK (Cancer Research UK 2007). It tends to grow more rapidly in depth and thickness than other types of melanoma and may not have a readily visible phase of radial development. Instead of arising from a pre-existing mole, it may appear in a spot where a lesion did not previously exist. It is found most often on the trunk or head and neck. As illustrated by figure 1.2 the melanoma usually appears as a blue-black, dome-shaped nodule, although 5% of lesions are pink or red and another 5% are amelanotic (have no pigmentation) which makes diagnosis more challenging. Nodular melanoma is more common in men than women and is most often seen in people aged over 60 but it can develop at any age (Melanoma Centre 2003).



Figure 1.2 Nodular Malignant Melanoma

#### Lentigo maligna melanoma

Lentigo maligna melanoma (LMM) typically occurs on sun-damaged skin in the middle-aged and elderly, especially on the face. This melanoma may be mistaken in its early, and most treatable, stages for a benign ‘age spot’ or ‘sun spot’. LMM accounts for about 10% (about 1 in 10) of the melanomas diagnosed in the UK. Since LMM is so easily mistaken, it can go undetected for years. This can be quite dangerous. Figure 1.3. is a picture of a LMM, which begins as a spreading, flat, patch with irregular borders and variable colours of brown. This type of melanoma grows very slowly, so it may be gradually getting bigger over several years and is often mistaken for lentigo simplex — a benign (non cancerous) brownish patch that can develop in the elderly after years of sun exposure. As the lesion grows deeper into the skin (thickness increases), it may become various shades of black and brown and begin to form lumps (nodules). These nodules are the invasive tumour, and if large enough to be felt by touch, will feel lumpy.



Figure 1.3 Lentigo Maligna Melanoma

#### Acral lentiginous melanoma

Acral lentiginous melanoma is the most common melanoma in Black and Asian people accounting for 50% of melanomas that occur in people with these skin types. Acral comes from the Greek word *akron*, meaning extremity, and the MM typically appears on the palms of the hand, soles of the feet (as in figure 1.4), or under the nails. It is much more common on the feet than on the hands. Lesions are usually tan, brown, or black, with variations in colour and irregular borders. These melanomas are often discovered later than other forms of melanoma because of the misconceptions that melanomas only occur in sun-exposed areas and that Black and Asian people are not at risk of melanoma (Franke et al 2000; Cormier et al 2006). A tendency to mistake the early signs of acral lentiginous melanoma for bruises or injuries to the palms, soles, or nail beds may further delay diagnosis.



Figure 1.4 Acral Lentiginous Malignant Melanoma

### 1.3 AETIOLOGY

MM is a malignancy with both an endogenous (internal) and exogenous (external) aetiology. The single most important exogenous factor is exposure to ultraviolet (UV) radiation (Gilchrest et al 1999; Armstrong and Kricger 2001; Cancer Research UK 2006), traditionally equated with exposure to the sun but more recently also with artificial sources of UV radiation, such as sunbeds and sunlamps. The endogenous factors which include skin phototype (the amount of melanin pigment in the skin), number of moles, having atypical melanocytic naevi (unusual moles) and having a family history of skin cancer, are also important predictors of melanoma risk (MacKie 1998; Tucker and Goldstein 2003).



### 1.3.1 EXOGENOUS FACTORS

Epidemiological studies have shown that the major exogenous aetiological factor of MM is sunlight exposure (Elwood and Jopson 1997; Bastuji-Garin and Diepgen 2002; Marks 2002). Having said this, epidemiological evidence for the causative role of sunlight is conflicting. The measurement of sun exposure is complex, and the relationship between MM and sun exposure has not yet been identified (Elwood and Jopson 1997; Ortonne 2002). The risk of melanoma appears to depend on the interaction between the nature of the sun exposure and the skin type. Sun exposure in childhood has been identified by most epidemiological studies as the major risk factor for the development of melanoma (Whiteman et al 2001). There is less evidence that sun exposure during adulthood contributes to the risk of MM. However, most of the evidence that the pattern of exposure is important relates to exposure in adulthood. Thus, it is impossible to exclude completely the effect of sun exposure in adult life on the risk of melanoma. Although different patterns of sun exposure are associated with different levels of risk for melanoma among individuals, it seems that intermittent sun exposure is associated with greater risk than total lifetime exposure (Elwood and Jopson 1997; Armstrong and Krickler 2001). A rise in outdoor recreational activities, the desire to tan and increases in high-altitude and (sub)tropical holidays have resulted in increasing levels of intermittent exposure to the sun. This is consistent with the rising trends that have been observed for MM by body site. As will be discussed later in the chapter, the more chronically exposed body sites like the head and neck exhibit lower incidence compared to intermittently exposed areas like the trunk and limbs (Severi et al 2000; MacKie et al 2002; De Vries et al 2003b).

The current recommended sun protection regimen in the UK, and across the world, includes wearing protective long-sleeved clothing, avoiding midday sun, and regular use of broad-spectrum high sun protection factor (15 or higher) sunscreen (Rigel 2002a; Cancer Research UK 2006). The association between reduced incidence of melanoma and sunscreens is still not clear. The results from the literature are controversial. Some studies showed a protective effect, while others showed increased risk of developing melanoma with sunscreen use. This is possibly due to people compensating for sunscreen use and increasing the duration of recreational exposure to the sun (Bastuji-Garin and Diepgen 2002; Stanton et al 2004). Since currently available data neither supports nor negates sunscreen use, the current recommendation is that sunscreen should be used as an adjunct to other forms of protection and not as a substitute (Dennis et al 2003; Doherty 2005).

The use of artificial sources of UV radiation, such as sun beds or sunlamps, has become popular in recent years for cosmetic or recreational purposes, particularly among teenagers and young adults in northern European countries (De Vries et al 2003a; Lens and Dawes 2004). Many clinical studies have reported that exposure to sunbeds or sunlamps has adverse effects on the skin and that their use might increase the risk of developing MM. An assessment of 19 epidemiological studies evaluating the association between sunbed/sun-lamp exposure and MM found that at this time, the published data are insufficient to determine whether sunbeds/sunlamps cause melanoma (Swerdlow and Weinstock 1998). As there were many methodological limitations in interpreting the results, further well-designed studies are needed. However, as De Vries et al (2003a) point out, it is unlikely that the use of sunbeds and sunlamps has influenced rising incidence

observed in population studies as their popularity is relatively recent. They go on to argue that these devices emit significant amounts of (mainly UVA) radiation and if UVA does have a causative role in the pathogenesis of melanoma, this might impact on future trends.

### 1.3.2 ENDOGENOUS FACTORS

The most important endogenous aetiological factor of MM is the presence of both common acquired and atypical (dysplastic) melanocytic naevi (moles) and risk increases with the number of naevi (MacKie 1998). People with very high numbers (100+) of common moles on their bodies have nearly seven times the risk compared to people with very few (0-15 moles) (Gandini et al 2005) and according to research carried out by Greene et al (1985) on 401 members of 14 families, people with dysplastic moles and a family history of melanoma (dysplastic mole syndrome) have a 500-fold increased risk of developing melanoma. A UK study of moles in twins concluded that the emergence of moles in adolescents is under strong genetic control (Wachsmuth et al 2001). These studies seem to indicate that patients with a family history of melanoma are at increased risk. Around 5-12% of patients with melanoma have a family history of MM in one or more first-degree relative (Goldstein and Tucker 2001). Some of these patients have inherited genes which are associated with a significantly increased risk of melanoma. To date, two melanoma susceptibility genes have been identified: CDKN2A (p16), and CDK4. Overall, approximately 20% of tested melanoma families showed inheritance of mutations in CDKN2A, while so far only three families have been found to have mutations in CDK4 (Newton Bishop et al 2000; Bishop et al 2002).

The colour of unexposed skin and the ability to tan - known as skin phototype - are both factors linked to melanoma risk. In 1975, Thomas B. Fitzpatrick of Harvard Medical School developed a classification system for skin typing (see Table 1.1). This system was based on a person's complexion and responses to sun exposure (Astner and Anderson 2004). Today, this classification system is widely used to categorise skin type. Accordingly, skin can be divided into six main groups. Individuals with skin type I and II have a higher risk of developing MM and there is an approximately three-fold risk increase associated with very pale skin compared to people with the darkest white skin (Mac Kie 1989; Armstrong and Kricger 2001). Eye colour may also be a factor- having blue eyes compared with people with brown eyes is associated with a modest increase in risk, although in some studies this is not a significant risk factor (Armstrong and Kricger 2001). Ideally, those groups of people who have been identified as being at a higher risk of developing MM should be the target for sun protection health promotion initiatives and education campaigns and this will be discussed further in later chapters.

Table 1.1 Fitzpatrick Skin Types

<b>Skin Type</b>	<b>Colour</b>	<b>Reaction to UV</b>	<b>Reaction to Sun</b>
Type I	Caucasian; blond or red hair, freckles, fair skin, blue eyes	Very Sensitive	Always burns easily, never tans; very fair skin tone
Type II	Caucasian; blond or red hair, freckles, fair skin, blue eyes or green eyes	Very Sensitive	Usually burns easily, tans with difficulty; fair skin tone
Type III	Darker Caucasian, light Asian	Sensitive	Burns moderately, tans gradually; fair to medium skin tone
Type IV	Mediterranean, Asian, Hispanic	Moderately Sensitive	Rarely burns, always tans well; medium skin tone
Type V	Middle Eastern, Latin, light-skinned black, Indian	Minimally Sensitive	Very rarely burns, tans very easily; olive or dark skin tone
Type VI	Dark-skinned black	Least Sensitive	Never burns, deeply pigmented; very dark skin tone

## 1.4 INCIDENCE

The following section outlines the incidence or occurrence of MM in the UK by age, sex, ethnicity, social class as well as global epidemiological trends. In order to provide a full picture of the impact of MM mortality and survival rates will also be discussed.

### 1.4.1 AGE

Although cancer can occur at any age, it is very much a disease of the elderly, with those aged over 65 being ten times more likely than those under 65 to develop cancer (Cartmel and Reid 1997). This is because with time, the likelihood of prolonged exposure to cancer

inducing agents increases, and the ability of the immune system to protect against cancer declines. In common with many other cancers, the prevalence of MM is highest in those aged over 75 but having said this, when compared with other cancers melanoma incidence is comparatively high in younger adults (Cancer Research UK 2006). This is evidenced by the fact that around a third of all cases occur in people aged less than 50 years and it is the second most common cancer in the 20-39 age group.

#### 1.4.2 SEX

Unlike most malignancies, malignant melanoma is more common in women than men with a male to female ratio of 2:3. In 2003 it was the sixth most common cancer in females in the UK and the eleventh in males: for both sexes combined it was the eighth most common cancer. The distribution of cases on the body also varies by sex (see Figure 1.5). Over a third of male cases arise on the trunk of the body, particularly the back, while the most common site for females is on the legs (Cancer Research UK 2006). Over the last twenty-five years, the incidence of malignant melanoma has increased more than for any other major cancer in the UK. The male rates have quadrupled from around 2.5 in 1975 to 11.0 in 2003, while the female rates have tripled from 3.9 to 12.6 over the same period (Cancer Research UK 2006)

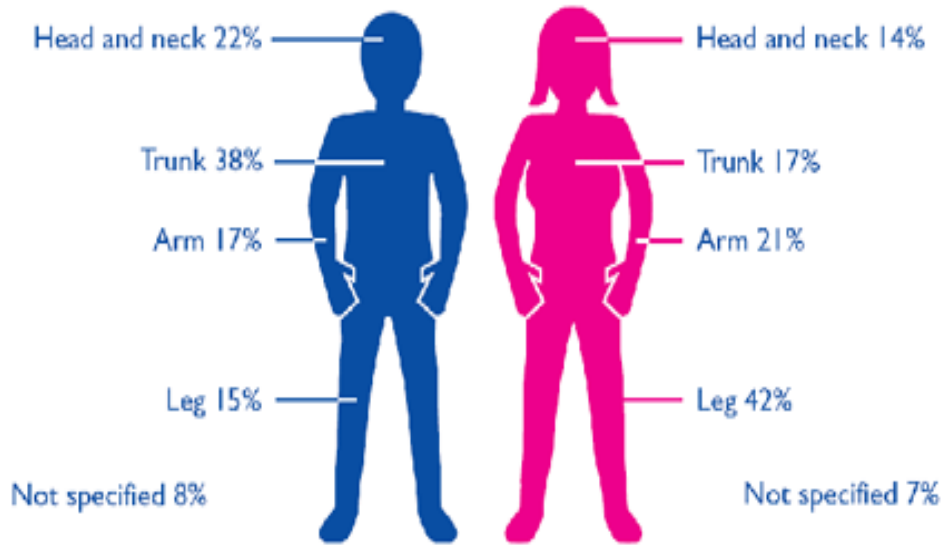


Figure 1.5 Percentage Distribution of Malignant Melanoma on Parts of the Body  
(Source: Cancer Research UK 2006)

### 1.4.3 ETHNICITY

Melanoma is primarily a malignancy of white individuals. Black people develop melanoma approximately one twentieth as frequently as white persons, and the prevalence in Asian people is approximately one sixth of that in white persons. However, mortality rates are higher in Blacks and Asians, who are more likely to have acral lentiginous melanoma and advanced disease at presentation (Cormier et al 2006). Franke et al (2000) attributed the poorer prognosis of acral lentiginous melanomas to a delay in diagnosis, reporting mean patient and physician delay times of 4.8 years and 7 months respectively, making a mean total of over five years before patients started receiving treatment. Given the atypical location of these lesions (palms of the hand, soles of the feet, or under the nails) and a lack of awareness of this disease entity in minority populations, it is not surprising that physician misdiagnosis has been reported as a common occurrence (Cormier et al 2006) further delaying potentially curative surgical treatment.

#### 1.4.4 SOCIAL CLASS

An unusual feature of MM is its positive association with affluence (Mackie 1989; Quinn et al 2001; Shack et al 2008). The ‘typical’ patient with superficial spreading and nodular MM is economically well off, has an indoor office-based occupation for forty eight weeks of the year, but is an avid sun bather for the holiday periods of the year, supporting the evidence that intermittent sun exposure is more important for risk compared to total lifetime exposure. Between 1993 and 1999 the age-standardised incidence rates for the most deprived areas in England and Wales were 60- 70% lower than those for the most affluent areas (Quinn et al 2001). More recently a study examining variation in incidence of breast, lung and cervical cancer and malignant melanoma by socioeconomic class in England found that if all socioeconomic groups had incidence rates similar to the least deprived group then the overall incidence of MM would increase by 27% in men and 29% in women (Shack et al 2008). If current differences in incidence are related to access to holidays abroad, where high intensity sun exposure is likely, then the gap between different deprivation groups is likely to narrow as more and more people can afford a ‘holiday in the sun’. According to the Office for National Statistics (2006) in 2005 UK residents made a staggering 66.2 million trips abroad, three times as many as in 1985. Two thirds of these foreign visits were holidays and just under half were package holidays.

#### 1.4.5 GLOBAL EPIDEMIOLOGICAL TRENDS

Since 1971, the incidence of MM has been increasing faster than any other cancer with an approximate doubling of rates every 10-20 years in countries with white populations (Lens and Dawes 2004). Globally, it accounts for 160, 000 new cases annually (Parkin et al



2005) and higher rates of incidence are found in Caucasian populations living in sunny climates. This increase in incidence and consequent mortality represents a significant and growing public health burden across the world. Until recently, Australia with over 8500 people diagnosed every year (Australian Institute of Health and Welfare 2004) claimed the highest incidence rates in the world. Statistical data reported in the year 2000 suggested that the lifetime risk of developing a melanoma in Australia was 1 in 25 for men and 1 in 34 for women, averaging an annual rate of 49.35 per 100 000 inhabitants (Burton 2000). Analysis of data obtained from Auckland, New Zealand in 1999 suggests that with an age-standardised annual rate of 56.2 per 100 000 people, this region now has the highest documented incidence of melanoma in the world (Lens and Dawes 2004).

It is estimated that there are 62 190 new cases of MM annually in America (American Cancer Society 2006) where it has become the most common form of malignancy and 1 in 71 (Rigel 2002b) people can expect to receive a MM diagnosis in their lifetime. This figure is expected to rise to 1 in 50 by 2010 (Rigel and Crucci 2000). Europe, like all other regions around the world occupied by largely white populations, has also witnessed a surge in MM incidence. The increases began first with Scandinavia where age-standardised rates as high as 20.7 per 100 000 population were recorded between 1995 and 1997 (De Vries et al 2003a) and then spread to western, southern and eastern Europe. Some of the increase may be explained by increased surveillance and early detection as well as changes in diagnostic criteria but most is considered to be real and linked to changes in sun seeking behaviour (Lens and Dawes 2004). In the UK, MM has seen the largest increase in incidence rates compared with other major cancers since the 1970s

(Cancer Research UK 2005) and statistics in 2004 placed the age standardised incidence rate at around eight per 100 000 people. More recent statistics show that the number of people diagnosed with MM has been steadily rising on a year by year basis and currently more than 8100 people are diagnosed with MM every year and the mortality rate stands at about 1800 per annum (Cancer Research UK 2007). On a positive note, there is evidence that suggests that in places like Northern Europe, Northern America and Australia where incidence rates are high, increases in melanoma incidence have begun to slow and in some areas may have reached a peak (De Vries et al 2003a; Lens and Dawes 2004). One of the possible explanations for this slowing in the MM incidence in these countries is increased awareness about the dangers of sun exposure leading to a decrease in unprotected or dangerous sun exposure practices and improved sun related behaviour. In spite of these encouraging changes, on a global scale the incidence of MM continues to rise at a faster rate than any other cancer. While the main preventable cause is known, the greatest challenge lies in translating this knowledge into changes in behaviour and this will be discussed at length in the third chapter of this thesis.

#### 1.4.6 MORTALITY

The number of deaths due to MM has also increased in most fair-skinned populations throughout the world in the past few decades. The death rate from melanoma continues to increase faster than the death rate for most cancers, with the exception of non-Hodgkin's lymphoma, lung cancer in women, and testicular cancer (Lens and Dawes 2004). Increases in mortality reflect increases in incidence but are much less pronounced due to the effects of earlier diagnosis and improving treatment. Latest statistics from Cancer Research UK (2007) show that there are currently about 1800 deaths from MM in the UK per annum.

Mortality rates rise steadily with age but substantial numbers of deaths occur in younger people. In 2004 over a hundred people aged under 40 died from this disease and half of all deaths were in people aged under 70 (Cancer Research UK 2006). A difference in trends in mortality from MM between the sexes also exists. Despite their lower incidence of melanoma, in common with most other countries, men in the UK exhibit higher mortality rates than women (De Vries et al 2003a). Melanomas in men present more often on the trunk (MacKie et al 2002; Cancer Research UK 2006) which has a poorer prognosis. A British descriptive epidemiological study, found that men have less knowledge about appropriate primary and secondary preventive measures, present with the disease at later stages and respond less to traditional public health education approaches (Streetly and Markowe 1995). This study is now over a decade old and whether these findings are still valid is discussed in later chapters (Chapter 7, 9 and 10).

Analysis of the data from the World Health Organization (WHO) Cancer Mortality Data Bank suggested that populations are currently at different places on the melanoma mortality epidemic curve (Severi et al 2000). In some countries (U.S.A., Australia, Nordic European countries, UK, Canada) a moderation or stabilisation of the rising trends in mortality has been reported in more recent birth cohorts, while in other countries a steep increase with no major changes in this trend was observed (central and southern European countries) (De Vries et al 2003b; Lens and Dawes 2004). As De Vries et al (2003b) point out, the countries with the highest incidence rates (Australia, New Zealand) also have the highest survival rates, whereas in those countries where incidence is low (Eastern and Central Europe), survival rates are relatively poor. This is probably due to a greater

awareness in high incidence countries possibly linked with government investment in targeted health promotion, resulting in earlier detection of melanomas and therefore better survival. Although mortality rates in the UK have been steadily increasing this could be as a result of past sun related behaviours and as such it will not be possible to determine the impact of current health promotion initiatives for a number of years.

#### 1.4.7 SURVIVAL

The most powerful predictor of survival for primary MM is tumour thickness at the time of diagnosis. Tumour or Breslow thickness (as it is usually called) is the measurement of the depth of invasion of the primary melanoma. It is named after the pathologist Alexander Breslow who in 1970 observed that as the thickness of the tumour increases, the chance of survival goes down (Breslow 1970). The measurement is determined by microscopically examining a section cut from the part of the melanoma which appears to be thickest, or is raised above the skin surface. The Breslow thickness measurement is the distance in millimetres from the granular layer in the epidermis to the deepest invasive tumour cell in the underlying dermis (Breslow 1970). The Breslow scale classifies MMs into three categories depending on how deep they are

- Low risk - the melanoma is less than 0.76mm thick
- Medium risk - the melanoma is 0.76mm to 1.5mm thick
- High risk - the melanoma is more than 1.5mm thick

Since Breslow thickness relates to the stage of the tumour, it has predictive value in terms of prognosis and management. Studies from all parts of the world confirm the merits of Breslow tumour thickness measurement as the single most important prognostic predictive factor. In North America, patients are more aware of the significance of Breslow

measurement and reportedly discuss tumour thickness with their doctors. In the UK, this measurement is used as the basis for clinical decision making (National Institute for Clinical Excellence (NICE) 2006).

Over the last twenty five years, survival from MM has continually improved. The latest estimates of five-year survival for patients diagnosed in 2000- 2001 is 78% for men and 91% for women. (Cancer Research UK 2007). Survival rates are even higher in Scotland, with a 5 year relative rate of 85% for men diagnosed in 1997 – 2001 and 94% for women. Data from the Scottish Melanoma Group (MacKie et al 2002) shows the strong association between survival and thickness of tumour at the time of diagnosis. 5-year survival for patients with melanoma thinner than 1.5 mm was 93% among males and 97% among females. Patients with thicker melanomas (particularly more than 3.5 mm) had a steep decrease in survival. Five-year survival in patients with melanoma thicker than 3.5 mm was 47% in men and 55% in women (MacKie et al 2002). The improvement in survival can be attributed to the earlier detection of melanoma. In the Scottish example Doherty and MacKie (1986) demonstrated the effectiveness of active public education campaigns aimed at encouraging earlier detection of melanoma leading to the diagnosis of thinner lesions with a better prognosis. However, despite the evidence showing improved survival rates, the death rate from MM continues to climb as a result of exponential increases in incidence, making it a major public health problem in the UK for the foreseeable future.

## 1.5 SYMPTOMS

Melanomas may have many different appearances. They can be small, shiny or waxy, scaly and rough, firm and red, crusty or bleeding, or have other features; as such the general rule of thumb is that anything suspicious should be looked at by a doctor. Approximately one third of melanomas develop from existing, normal moles and the rest from previously normal skin. In order to determine which pigmented lesions require further investigation a seven-point checklist outlined below (Table 1.2) may be used (MacKie 1989; Cancer Research UK 2006).

Classically, the 'ABCDE' mnemonic (Table 1.3) has been used to describe these common characteristics of a melanoma. The presence of any major feature is a strong indication that MM is a possible diagnosis and rapid referral is recommended. The presence of one or more minor signs adds to the possibility that the diagnosis is MM. It has been suggested (MacKie 1989) that the presence of each major feature scores two points and each minor feature one point. Patients with any one of the three major signs or a score of three or more should be referred for specialist care, usually provided by a dermatologist

Table 1.2 Seven- Point Malignant Melanoma Checklist  
(Source: Atlas of Dermoscopy 2004)

**MAJOR FEATURES**

1. *Change in size* of previous lesion or obvious growth of new lesion
2. *Irregular colour*: a variety of shades of brown and black in a new or old lesion
3. *Irregular shape*: asymmetry and an irregular outline of a newly developed pigmented lesion or appearance of this feature in an old lesion

**MINOR FEATURES**

4. *Diameter* larger than 6mm in size
5. *Inflammation*: rare in benign lesions unless they are regularly traumatised
6. *Oozing, crusting or bleeding* of the lesion
7. *change in sensation*: usually described as a mild itch

Table 1.3 The ABCDE Mnemonic

- **A**symmetry: any mole or lesion that is asymmetrical
- **B**order: any mole or lesion that has an irregular border
- **C**olour: any mole or lesion that has variability or has had a recent change in colour
- **D**iameter: any mole or lesion that is greater than 6 mm in diameter
- **E**levation: any mole or lesion that is elevated

## 1.6 PREVENTION

Cancer prevention has been defined as being all measures that limit the progression of disease at any time during its course (Smith and Padberg 2005). Prevention measures can occur anywhere along the health continuum. Three levels of prevention: primary, secondary and tertiary have traditionally been identified in the nursing literature. Primary prevention seeks to avoid the onset of cancer, secondary prevention activities concentrate on early diagnosis and intervention and tertiary prevention activities involve rehabilitation and restoration to optimal levels of functioning (Smith and Padberg 2005). Primary and secondary prevention are both important with regard to MM. Primary prevention strategies are the steps taken to keep the malignancy from developing and include strategies such as decreasing UV exposure, properly applying sunscreen and wearing protective clothing. Public education programmes are the most common means employed to address these primary prevention strategies. Secondary prevention efforts include attempts to detect MM early in asymptomatic individuals by encouraging them to engage in practices like skin self-examination and annual check-ups by professionals. Table 1.4 is adapted from Mahon and Yackzan (2000) and provides an overview of primary and secondary prevention strategies and education points for MM and these will now be discussed in further detail.



Table 1.4 Primary and Secondary Malignant Melanoma Prevention Strategies

Strategy	Patient Education	Strengths	Limitations
<p>Reduce ultraviolet radiation (UVR) exposure (primary prevention)</p> <p>Avoid use of indoor tanning devices (primary prevention)</p> <p>Use chemical sunscreens correctly and consistently (primary prevention)</p> <p>Apply zinc oxide (a physical block) to sun-exposed areas (primary prevention)</p>	<p>Decrease sun exposure between 10 A.M. and 3 P.M. Instruction that UVR is present on cloudy days Infants 6 months of age and under should not have direct UVR exposure</p> <p>Large amounts of UVR are potentially carcinogenic Tanned skin is not healthy, rather it is a sign of injured skin Use of indoor tanning devices may lead to premature aging of skin and cataract formation</p> <p>Use a sun protection factor (SPF) of at least 30 that is waterproof Apply a test dose to check for allergies Apply liberally (about 30 grams for an adult in a swim suit) to all exposed skin surfaces 15-30 min prior to sun exposure Depending on the SPF reapply sunscreen frequently and especially after towelling off</p> <p>Apply a visible, liberal coat to sun-exposed areas Block is effective as long as a visible coat is seen on skin</p>	<p>Decrease carcinogen exposure</p> <p>Large source of carcinogen exposure which can be avoided</p> <p>When used correctly, sunscreen will block most of the UVB exposure and a variable amount of UVA</p> <p>Excellent for areas with a tendency to burn such as the nose, back of ears Is more waterproof than chemical sunscreens</p>	<p>Personal practices may be difficult to change- people may not feel motivated to behaviour</p> <p>Personal practices may be difficult to change - many people believe they look healthier with a tan</p> <p>Some consider sunscreens expensive and inconvenient to use Many people do not apply products prior to exposure, apply in adequate amounts and do not reapply when indicated, thereby limiting the effectiveness of the agents</p> <p>Unsuitable to be applied to all sun-exposed areas because of the amount of product necessary</p>

Wear protective clothing (primary prevention)	Protective clothing with a tighter weave can provide an effective physical block against UVR Shirts with sleeves and hats with wide brims provide more protection	Provides a means to directly reduce direct UVR to skin surfaces Relatively inexpensive Easy to apply	Patients may forget to wear hats or not see the benefits of protective clothing as worth the effort
Take extra precaution to reduce UVR exposure when taking photosensitising medications (primary prevention)	Teach patients about classes of photosensitizing medications and the need for extra protection	Reduces severe sunburns and UVR exposure	Patients may forget to take precautions or underestimate the dangers of photosensitising medications
Risk assessment (secondary prevention)	Define and interpret individual risks for developing skin cancer	Patients who understand their personal risk for developing skin cancer may be more motivated to practice prevention strategies	Time-consuming Patient must be motivated to assist with and try to understand assessment Requires skilled health care providers
Practice monthly skin self-examination (secondary prevention)	Demonstrate technique on the patient Point out any potential problems that require extra monitoring Teach patients to perform in a well-lit area and to pay attention to hard-to-see areas as well as sun-exposed areas	Inexpensive Can be done in privacy of own home Patient may be able to note an early interval change	Patients often forget to do examination or do not see the value of self-examination Some areas of body may be difficult for patient to adequately examine Patients may lack confidence in ability to detect a change
Annual professional examination (secondary prevention)	Opportunity to review many primary prevention strategies Teach skin self-examination Detect lesions that may not be immediately obvious to the patient	May detect subtle, early changes in lesions	May result in removal of borderline lesions Dependent on the skill of the examiner Most cost-effective in higher risk patients—cost effectiveness in the general population is not known

Mahon and Yackzan (2000)

### 1.6.1 PRIMARY PREVENTION IN MM

Since the majority of skin cancers can be prevented by avoiding UV radiation (International Agency for Research on Cancer 1992), numerous countries have launched public awareness campaigns whose main message is avoidance of the sun. In Australia such campaigns have been running for more than 20 years and have been credited with the high level of skin cancer awareness and sun safe behaviour now evident there (Marks 1999; Montague et al 2001; Miles et al 2005). In the UK similar efforts have been more sporadic. The last national campaign began in 1995 but ended in 2000 with the demise of the Health Education Authority. Subsequently, Cancer Research UK was awarded funding by the government to run a nationally co-ordinated ‘SunSmart’ campaign modelled after the highly successful one in Australia. Based on currently recommended sun protection strategies applied across the world, the main messages of the SunSmart campaign centre on five key actions people should take to protect against UV damage presented under the acronym: SMART (see Table 1.5)

Table 1.5 The SMART Mnemonic

- **S**pend time in the shade between 11 and 3
- **M**ake sure you never burn
- **A**im to cover up with a hat, T-shirt and sunglasses
- **R**ember to take extra care with children
- **T**hen use factor 15+ sunscreen or higher

Cancer Research UK 2007

The SunSmart campaign especially targets individuals who are at higher risk of getting MM (see section 1.3 for description of higher risk category individuals) and urges them to take extra care in the sun.

In an excellent article about the public health approach to preventing and controlling MM, Marks (1996) outlines measures of outcome that can be used to assess the short, medium and long term results of primary prevention programmes. Short-term goals should include an increase in knowledge about the importance of sun protection and a decreased desire for a suntan. Until these two goals are achieved, it is Mahon and Yackzan's (2000) assertion that primary prevention strategies will not be implemented effectively. Medium-term goals of primary prevention programmes should include an increased use of hats, clothing, shade, and sunscreens that results in a decreased number of sunburns. Truly effecting these changes in behaviour so that they are practiced from childhood through adulthood is probably very complicated and difficult to accomplish. Ultimately, the long-term goals of primary prevention programmes include a decrease in the incidence of and mortality from MM. These long term benefits may not be evident for at least two decades (Diffey 2004) although a higher proportion of individuals enjoying the sun more safely can only be good news.

### 1.6.2 SECONDARY PREVENTION IN MM

The whole ethos of secondary prevention lies in the detection of disease early in its trajectory. As will be discussed in the next chapter, late presentation by MM patients is possibly the most significant reason for late diagnosis and the development of effective

secondary health promotion strategies is dependent on establishing the reasons for late presentation (Dunkley and Morris 1991). This is the major aim of this thesis.

The literature regarding detection of early melanoma concludes that increasing awareness of melanoma among the public, especially those at risk, is critical for preventing mortality, especially in the absence of effective treatment for advanced disease. A consensus statement from experts within the field of dermatology, pathology, epidemiology and public education in the United States states that public education campaigns have a positive effect on early detection of melanoma and that education and screening programmes have the potential to decrease morbidity and mortality from melanoma (National Institute of Health 2002). This statement was compiled by an independent panel and was based on presentations by investigators working in the areas relevant to the consensus questions, questions and statements from conference attendees and from closed deliberation by the expert panel. Unfortunately there is no information given on the evidence behind the statements and this makes it difficult to judge the merit of these findings.

The term 'screening' is often used synonymously with 'early detection' or 'secondary prevention' however it is important to draw a fundamental distinction between these terms. Early detection refers to an attempt to diagnose cancer at a curable stage, whereas cancer screening is just one of the strategies used to achieve this goal (Mahon 2005). A protocol published by the Cochrane Database of Systematic Reviews (2002) states that the aim of screening is to identify individuals who may have a previously unrecognised

disease or condition. Marks (1996) and Mohan and Yackzan (2000) identify several approaches to screening for skin cancer and these are:

- **Skin self examination (SSE)** which is characterised by regular (usually monthly) examination of all skin surfaces
- **Opportunistic screening** which is the sporadic examination of patients who present for other health reasons (usually done by the GP)
- **Professional skin examination** which is an annual examination of all skin surfaces by a trained health professional with the goal of detecting skin cancers early
- **Mass screening** which is a population based screening of asymptomatic patients at a defined clinical site on a specific date
- **Surveillance** which is a regular examination (usually every 3- 6 months) of patients with a high risk of developing skin cancer.
- **Genetic testing** which comprises of DNA studies to determine if a patient who has a hereditary predisposition to MM carries susceptible genes

None of these approaches is perfect; each has its own inherent strengths and weaknesses. For example, while large numbers of people can be examined by professionals in a relatively short period of time and early signs of MM detected by mass screening, the literature regarding this type of screening concludes that it is not cost-effective and lacks efficacy (Koh et al 1995). An audit paper by Holme et al (2001) reports that the rate of people identified from mass screening events is significantly lower than that of the cancer referral clinics that most dermatology units already operate. This paper, reaches the same conclusion as others (Weinstock 1990; Koh et al 1991; Elwood 1994) that the most cost

effective way of public screening is probably targeting 'at-risk' groups such as outdoor workers. This could be one of the services provided by occupational health departments although many 'outdoor' workers might be self employed and as such be less likely to have access to such facilities. The challenge, therefore, is to select a screening approach that best meets the requirements and resources of the situation.

The aim of early detection in melanoma is to reduce the mortality rate due to the tumour. A secondary benefit of this is a reduction in the management and intervention required for the tumour (Marks 1996). The major short term goal of secondary prevention is an increase in the public's knowledge about the signs and symptoms of MM that require medical attention. Medium term goals include an increasing number of people seeking attention for early melanoma, an increase in the number of thin melanomas detected and a decrease in the number of thick melanomas. The ultimate goal of secondary prevention in MM is a reduction in the mortality rates. Having said this, the efficacy of both early detection and screening programs remains untested by randomised trials (Geller et al 2002) and although smaller studies have alluded to their potential value, further research is required.

## 1.7 TREATMENT

This next section discusses the current recommended treatment and possible adjuvant therapies regimes for MM available in practice. First however, an explanation of staging used in MM which determines the type of treatment a patient receives will be offered.

### 1.7.1 STAGING MELANOMA

Accurate staging is vital for managing patients with cancer effectively. There were several methods for staging MM used in the 1980s and 1990s all of which have now been replaced by a single system developed from the existing American Joint Committee on Cancer (AJCC) staging system (Balch et al 2001a). This system, outlined in Table 1.6 was developed from data collected on more than 17,000 patients and provides clearer, more accurate prognostic categories (Balch et al 2001b). The system is based on information about the primary tumour (T), the regional lymph node status (N) and the presence of distant metastases (M). Primary melanoma is divided into four groups, according to histological thickness: under one millimetre in thickness (T1), between one and two millimetres (T2), between two and four millimetres (T3) and above four millimetres (T4). Normal regional lymph nodes are designated as N0, whereas one involved node is designated as N1, two to four nodes as N2 and more than four nodes as N3. Metastases found in between the primary site and the regional nodes - local or in-transit metastases - are included in the N category.

Although individuals who develop distant metastases are likely to die from their disease, rates of progression vary between better prognosis skin and distant lymph node metastases (M1), and increasingly worse prognosis lung (M2), and liver and brain (M3) secondaries (Balch et al 2001b; Marsden 2006). Unexpectedly, the analysis showed that ulceration of the primary melanoma worsened an individual's prognosis right through the disease, for example, a patient with a non-ulcerated primary melanoma and a single lymph node metastasis has about a 50-60% chance of cure, whereas if the primary metastasis is



ulcerated and there is a single node, the chance of cure is less than 30% (Balch et al 2001a).

Table 1.6 Cancer Staging System

Stage	TNM Classification	Breslow thickness and Ulceration Status	5-Year Survival Rate, %
0	Tis N0 M0	Intraepithelial/in situ melanoma	100
IA	T1a N0 M0	≤1 mm without ulceration and level II/III	>95
IB	T1b N0 M0	≤1 mm with ulceration or level IV/V	89-91
	T2a N0 M0	1.01-2 mm without ulceration	
IIA	T2b N0 M0	1.01-2 mm with ulceration	77-79
	T3a N0 M0	2.01-4 mm without ulceration	
IIB	T3b N0 M0	2.01-4 mm with ulceration	63-67
	T4a N0 M0	≥4 mm without ulceration	
IIC	T4b N0 M0	>4 mm with ulceration	45
IIIA	T1-4a N1a M0	Single regional nodal micrometastasis, nonulcerated primary	63-69
	T1-4a N2a M0	2-3 microscopic positive regional nodes, nonulcerated primary	
IIIB	T1-4b N1a M0	Single regional nodal micrometastasis, ulcerated primary	46-53
	T1-4b N2a M0	2-3 microscopic regional nodes, nonulcerated primary	
	T1-4a N1b M0	Single regional nodal macrometastasis, nonulcerated primary	
	T1-4a N2b M0	2-3 macroscopic regional nodes, no ulceration of primary	
	T1-4a/b N2c M0	In-transit metastasis and/or satellite lesion(s) without metastatic lymph nodes	
IIIC	T1-4b N2a M0	Single macroscopic regional node, ulcerated primary	24-29
	T1-4b N2b M0	2-3 macroscopic metastatic regional nodes, ulcerated primary	
	Any T N3 M0	4 or more metastatic nodes, matted nodes/gross extracapsular extension, or in-transit metastasis/satellite lesion(s) and metastatic nodes	
IV	Any T any N M1a	Distant skin, subcutaneous, or nodal metastasis with normal Lactate Dehydrogenase (LDH) levels	7-19
	Any T any N M1b	Lung metastasis with normal LDH	
	Any T any N M1c	All other visceral metastasis with normal LDH or any distant metastasis with elevated LDH	

Adapted from Balch et al 2001a

Ulceration is also an important predictor of local metastatic risk. A critical examination of the AJCC staging system reveals that like any other system it has its shortcomings. As Mardsden (2006) points out, it fails to take into account all known prognostic determinants and is not intuitive to use. Never the less it has been well received across the world because it is practical, reproducible, applicable and accurately reflects the clinical biological behaviour of MM (Ruiter et al 2001). In addition, because the AJCC staging system is evidence based and takes into account the dominant prognostic factors that have been consistently identified in appropriate multivariate regression analyses (Ruiter et al 2001; Balch et al 2001a) it aids practitioners in their clinical decision making as well as when comparing treatment results.

### 1.7.2 TREATMENT

Surgery is currently the only curative treatment for primary MM. Detailed guidelines on the treatment of MM in the UK have been published by professional bodies like the British Association of Dermatologist and the Melanoma Study Group (Roberts et al 2002). In addition, the National Institute for Health and Clinical Excellence (NICE) (2006) has produced an extensive guide on the organisation of services and treatment options for skin cancer patients by the NHS in England and Wales. As a general guide, based on evidence obtained from randomised control trials, NICE (2006) recommends that lesions that are suspected as MM should be initially excised as full thickness skin biopsies. These should include the whole lesion with a two to five millimetre clinical margin of normal skin and a cuff of sub-dermal fat to enable an accurate histopathological report including a measure of Breslow thickness (Cancer Research UK 2006). The surgical excision margins (usually one to three centimetres) for histologically confirmed invasive MM are determined by

Breslow thickness (Roberts et al 2002; NICE 2006). However, the suggested margins may have to be adjusted for cosmetic or functional reasons, for example around the eye (Roberts et al 2002).

Patients with early stage disease (stage IA, IB and IIA), when the tumours are thin and have no nodal spread, can be treated with surgery alone as they have good to excellent prognosis with five year survival rates in excess of 78 percent (Roberts et al 2002; Cancer Research UK 2006). However, as tumour depth increases, so excision margins widen and survival is worse as risk of developing nodal metastases directly relates to tumour thickness. Sentinel node biopsy (SNB) is increasingly being used to determine nodal spread. This technique, developed in the early 1990s, is now well established and has the advantage of limiting unnecessary radical node dissections by selecting patients who might benefit from such a procedure. It is now known that if the sentinel node is negative, it is very unlikely that there is MM in the regional basin- groin, axilla or neck (Marsden 2006). About 20 percent of sentinel nodes are positive. This allows comparison between wide excision only and wide excision with elective lymph node dissection, only in patients with a positive sentinel node. However, according to NICE (2006), although there is good evidence that SNB for MM may be useful as a staging investigation, there are, as yet, no randomised controlled trials reporting on survival after SNB and as such no statistically significant advantage in terms of overall mortality has yet been established.

### 1.7.3 ADJUVANT TREATMENT

Patients with stage IIB or above are at risk of recurrent disease as there is currently no strong research evidence to show that any adjuvant systemic treatment helps to stop

melanoma from recurring or spreading. In the UK they can only be offered this type of treatment within a clinical trial (Roberts et al 2002; Cancer Research UK 2006). Most trials require entry within eight weeks of completion of surgery so patients at intermediate or high risk of relapse ideally should be referred to a specialist multidisciplinary team based at a Cancer Centre promptly (Roberts et al 2002). Adjuvant therapies currently under investigation include immunotherapies such as interferon, vaccines and chemotherapy (Cancer Research UK 2006). Interferon is licensed for adjuvant use in the UK, however because of the side-effects commonly experienced such as fatigue, flu-like symptoms, fever, headaches (Cancerbackup 1997), more confirmatory trials with mature data are considered necessary before it can be recommended as standard treatment (Roberts et al 2002). Treatment for patients with metastatic disease may include further surgery to remove metastatic disease, single agent chemotherapy with decarbazine and palliative radiotherapy (Cancer Research UK 2006).

A number of clinical trials are ongoing to identify more effective treatment for both early and late stage MM and standard therapy options may be modified and improved in light of further information. In the absence of more effective treatment for advanced tumours, early recognition and treatment of localised tumours is at present the most effective way of reducing mortality once melanoma has developed (Schmid-Wendtner et al 2002). As such, early presentation is crucial in terms of outcome. This largely depends on the ability of an individual to recognise a suspicious lesion and rapidly seek medical attention (Richard et al 2000a). Unfortunately this does not always happen, sometimes with fatal consequences. The major aim of this study is to understand why some individuals appear

to delay in presenting with their signs and symptoms for diagnosis and treatment. As such, the next chapter will explore the literature that serves as a background to understanding delay in MM and examine the factors that impact on the decision making associated with seeking medical assistance.

## **2. CHAPTER TWO**

### **PREDIAGNOSTIC DELAY IN MM**

#### **2.1 INTRODUCTION**

As highlighted by the previous chapter, in MM survival prospects are associated with early detection, thickness of tumour and the presence of ulceration at the time of diagnosis. When detected and treated early, individuals usually have a highly favourable prognosis (Oliveria et al 1999). Nevertheless a substantial number of people present for treatment with extensive invasion of disease on diagnosis. There is limited evidence examining why presentation delay occurs, something this study sought to rectify. This chapter examines the literature concerning presentation delay in MM. The first part provides a brief overview of the process of seeking medical help for cancer symptoms in England. The second, and more substantial, part explores the concept of presentation delay and offers a working definition for 'delay' that will be used throughout the rest of the thesis. The final part of the chapter presents a review and critique of the published research relating to presentation delay in MM. The purpose of this chapter is to provide both a rationale and backcloth for the study by providing an overview of the current issues associated with presentation delay in MM, and signposting how the present study seeks to build upon the existing knowledge.

#### **2.2 SEEKING MEDICAL HELP**

Generally speaking, seeking medical help for what might be symptoms of cancer is a relatively uncommon response. This is because symptoms are common, unspecific and the

majority are transient and benign. The major problem with cancer symptoms is the non-specific nature of many of the warning signals in apparently healthy people (De Nooijer et al 2001b). In an ideal situation, an individual would be able to detect a symptom, infer illness, decide to seek medical attention and visit a health care provider, usually their general practitioner (GP), without delay. In England, patients with cancer enter the health care system by a number of routes. The first point of call is usually their GP. For some the suspicion of cancer is high when they are first seen by a GP. According to the Department of Health's Cancer Plan (2000a), these patients should be urgently referred for assessment, ideally within two weeks. In some parts of the country this will be to a 'pigmented lesion' clinic which operates on a 'no waiting list' principle. In other areas referral will be directly to the local dermatologist, surgeon or plastic surgeon that has an interest in pigmented lesions. The vital point is that suspicious lesions have grounds for urgent referral and the patient should be seen quickly, usually within the week, and not placed on a long waiting list.

The simple diagram below (Figure 2.1) is adapted from the Cancer Plan (2000a) and depicts the ideal presentation journey. In this journey the patient assesses their symptoms, infers illness and immediately seeks their GP's assistance. The GP in turn assesses the symptoms, recognises the disease and quickly refers the patient to the appropriate specialist. Within a week or two the patient has received a hospital assessment and is well on their way to being diagnosed, discussing treatment options and beginning their treatment.

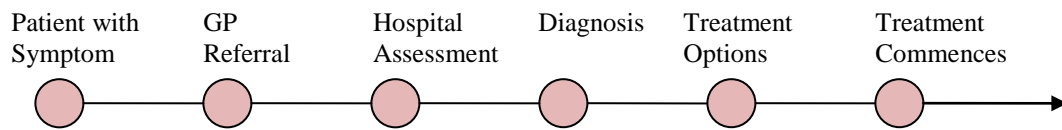


Figure 2.1 The Ideal Presentation Journey

The patient journey described here, is one that runs smoothly with no problems, deviations or delays and clearly is an ideal. However, as with most things, the reality is often quite different. For a multitude of reasons, the individuals fail to seek medical assistance promptly thereby introducing a delay in treatment. Added to this, in some cases the GP may initially fail to suspect cancer and this is a general concern with all cancers and MM in particular. Patients may be inappropriately reassured there is nothing to worry about and sent home. Alternatively, they may be given ineffective regimes of treatment such as steroid creams to observe if they have any curative benefit before further action is taken, thereby lengthening the period of delay before correct diagnosis and treatment commences.

Guidelines such as NHS Cancer Plan (2000a), the Cancer Reform Strategy (2007), the SIGN guidelines (2003) and the National Institute for Clinical Excellence (NICE) guidelines (2006) all provide a framework for the most desirable and effective ways of treating MM. They emphasise that the absence of more effective treatments for advanced tumours places particular importance on recognising and treating localised tumours early. This is potentially the most effective way of reducing mortality once melanoma has developed. While this is undoubtedly true, obtaining an early MM diagnosis is largely



dependent on the ability of an individual to recognise a suspicious lesion and rapidly seek medical attention (Richard et al. 2000a). Unfortunately this does not always happen. A number of studies have suggested that the visible signs and symptoms of early melanoma do not always prompt individuals to seek medical care (Oliveria et al 1999; Richard et al 2000a; Negin et al 2003). Failure to take action after noticing a suspicious symptom or change in an existing lesion leads to presentation delay. This is one of the major challenges in melanoma care and will now be discussed further.

### 2.3 PRESENTATION DELAY

As long ago as 1954, Charles Cameron, the medical and scientific director of the American Cancer Society, said two out of every four people diagnosed with cancer in the next year (1955) *could* be saved by current methods of treatments. However, he went on to add that only one of those *would* be saved. The other would delay seeking help until his or her disease had progressed too far for them to be helped by even the most modern methods (Blackwell 1963 cited in Antonovsky and Hartman 1974). Half a century later his sentiments still resonate in modern health care. Presentation delay continues to be one of the greatest challenges in cancer care. Based upon a review of nearly four decades of research concluded in 1974, Antonovsky and Hartman generalised that between 35% and 50% of cancer patients delay three months or more in seeking treatment. No recent reviews have been found that challenge these figures.

It is not difficult to compile an impressive list of evidence, academic, clinical or contemporary, that testifies to the importance of cutting down the delay which, regrettably, precedes therapeutic interventions for cancer patients. Even as far back as the

1930s when presentation delay was beginning to receive an interest in the literature (Pack and Gallo 1938) dominant professional opinion tended to coincide with common sense in arguing that the earlier the patient accessed professional attention, the more likely it was for their life to be saved (Antonovsky and Hartman 1974). Unfortunately, it would seem delay is an inevitable part of most cancer journeys with patients, doctors and the health care systems all contributing to it. Arguably, it is not possible to completely eliminate it from practice (Antonovsky and Hartman 1974; Sisler 2003), and as such distinctions between avoidable and unavoidable delay are sometimes made. No matter how sophisticated the society, it is not possible to access, diagnose and treat a patient in the same day and waiting for appointments, biopsy results and surgery are all part of the journey to diagnosis and treatment. The perception of whether delay is excessive or reasonable is very subjective and it is therefore prudent for any study that wishes to explore this problem to offer a working definition in the context of the study.

### 2.3.1 THE DEFINITION OF DELAY

Several definitions have been used by studies examining delay in seeking medical attention for symptoms- the most frequent being the one first employed by Pack and Gallo in 1938. They define delay in patients as the failure to seek medical care for suspicious symptoms within three months of their recognised appearance by the patient. Any elapsed time beyond this 90 day criterion places the individual in the ‘delaying’ or ‘procrastinating’ category. They also define physician delay as occurring when more than one month elapses between the initial consultation with the doctor and the establishment of diagnosis or referral for appropriate treatment. However, there are certain major difficulties presented by this approach. To begin with, it is widely acknowledged that

cancer symptoms may occur insidiously and may express themselves in devious and unsuspected ways whereas other symptoms are easier to recognise. For example, a patient with an amelanotic MM (melanoma without the melanin pigmentation that shows up as a pink growth) is likely to take longer to seek medical attention than someone with a darkly pigmented MM. Clearly, people respond at different rates to symptoms appearing on different body sites with differing degrees of intensity or discomfort (Cassileth et al 1988; Brady et al 2000; Baade et al 2006). Thus delay may be a reflection of the individual's symptom experience and cannot be reduced to an arbitrary time criterion. Then there is the related factor of how patients perceive their own behaviour. It should be emphasised that 'delay' has both an objective and subjective meaning. As such, an important question to ask would be how closely does the doctor's objective determination of delay correspond to the patient's perception of their own behaviour? It might well be that some patients who delay beyond the so-called medically safe three month period consider their help seeking behaviour as reasonable and do not consider their own search for diagnosis as delayed.

Another problem presented by using the three month time criterion to define delay is the fact that by and large most studies are based on patients' recollections of events and as Antonovsky and Hartman (1974) point out, it is very rare that the studies explicitly state what question was asked to determine the extent of delay. Nothing was found that established the reliability of such recollections, much less their validity. Since patient delay is, by its very definition, a time period during which important physical symptoms are occurring without the benefit of appropriate clinical attention, it is reasonable to

assume that there might be a significant amount of underreporting and therefore recollections of time frames may consistently be inaccurate.

A general overview of MM literature suggests that there is no consensus regarding what actually constitutes a 'delay' in MM presentation. Different studies have therefore resorted to defining delay, not so much in terms of the three month criterion, but rather by estimating the average time it takes for patients to receive a diagnosis of, and treatment for MM. These estimates are often broken down into patient and doctor components and vary widely. One UK based study (Duff et al 2001) of 9968 patients attending a Bristol pigmented lesion clinic (PLC) provides an estimate of delay in diagnosis of MM due to doctors of between 5 and 41 months. In the same vein, a large French study (Richards et al 1999) reported that patients averaged 21 months (range 0 – 57 months) between the point when the lesion was first noticed and resection and an oft cited American study (Oliveria et al 1999), placed the mean delay time at two months (range 0.5- 22 months). Most studies, however, report an average total delay (patients, doctors and the system) in diagnosis of not more than 12 months (Cassileth et al 1988; Dunkley and Morris 1991; Krige et al 1991; Blum et al 1999; Brochez et al 2001; Montella et al 2002; Schmid-Wendtner et al 2002; Betti et al 2003).

### 2.3.2 AN ALTERNATIVE DEFINITION OF DELAY: TUMOUR THICKNESS

In this study Breslow thickness was the yard stick used to define delay. Individuals with thick melanomas (>0.76) were automatically eligible to be entered in the study. However, using tumour thickness as an indication of delay is in itself controversial. Although the correlation between the delay in diagnosis and prognosis is universally acknowledged, it

has never been robustly established (Richard et al 1999). Using thickness as a surrogate for prognosis, a number of studies have attempted to establish whether tumour thickness is related to delay (DiClemente et al 1982; Temoshok et al 1984; Temoshok et al 1985; Cassileth et al 1988; Krige et al 1991; Richard et al 1999; Richard et al 2000a; Richard et al 2000b; Brochez et al 2001; Montella et al 2002; Betti et al 2003), some with greater success than others. For instance in a now rather dated study of 104 patients at the University of California, DiClemente et al (1982) expressed the view that patient delay is indeed a crucial factor associated with thicker lesions, higher medical risk, poorer prognosis of melanoma and consequently, a higher probability of mortality. This view is strongly supported by studies such as Montella et al (2002) and Betti et al (2003). Although others (Temoshok et al 1984; Temoshok et al 1985; Cassileth et al 1988) have also reported the connection between tumour thickness and delay, this is often an incidental finding from studies investigating other issues. On the other hand a few studies reveal no association between delay and increased tumour thickness (Austoker 1994; Richard et al 2000a; Richard et al 2000b; Baade et al 2006; Baumert et al 2007). Despite this unclear and far from final picture, delay in MM presentation continues to be a widespread problem and in at least some cases is associated with thicker, deeper tumours and a less favourable prognosis. As such, it follows that there is wisdom in trying to minimise delay for all patients as this might mean the difference between life and death.

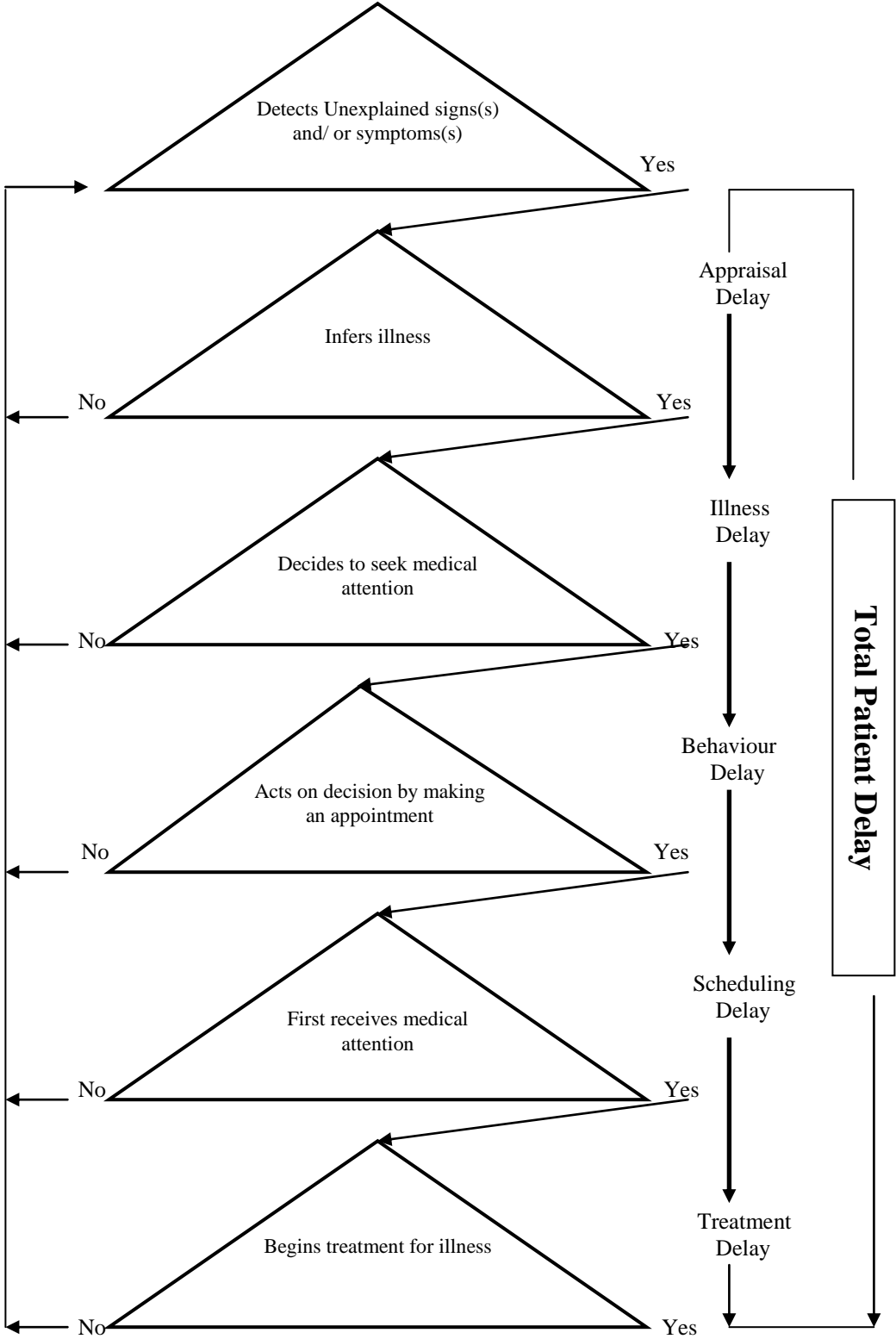
### 2.3.3 MODEL OF DELAY

Regardless of which definition of delay has been used, studies examining presentation delay in MM have lacked a theoretical model. While *defining* delay by an arbitrary

criterion leaves much to be desired, *measuring* delay in terms of time still remains the best compromise to encompass all types and sites of cancer in all population groups. Studies of delay have demonstrated that segmenting the total delay period into sequential ‘periods of delay’ can facilitate the search for specific causes, that is, when delay occurs and why, as well as the differences between individuals regarding the principal cause of their delay (Antonovsky and Hartman 1974; Safer et al 1979; Andersen et al 1995). This can be represented diagrammatically and figure 2.2 is an adaptation of Andersen et al’s (1995) Model of Patient Delay. This model is based on earlier work by Safer et al (1979) and has been applied to a variety of physical disorders. The model describes the pre-diagnostic period as comprising of five stages in which delays can occur. The stages are; appraisal delay, illness delay, behavioural delay, scheduling delay and treatment delay. Each stage is dichotomous and a move to the next stage is determined by decisions and interpretations in the previous stage.

**Appraisal delay-** This is the period of time taken by an individual to interpret a complaint as a cancer symptom or at least as a serious symptom that needs attention (de Nooijer et al 2001a). Andersen et al (1990) and Andersen et al (1995) hypothesise that this first interval accounts for the majority (75%) of delay in seeking a cancer diagnosis. This is largely because the development of malignancy and the appearance of cancer symptoms is often protracted, and a complex and changing symptom experience can be typical (Andersen et al 1995). Earlier work by Safer et al (1979) revealed that different factors are more important in different stages of delay. During appraisal delay, the sensory experience of a symptom has the greatest impact on delay- for instance, patients recognise a symptom as an

Figure 2.2 The Model of Patient Delay



indication of illness more quickly if they experience severe pain or bleeding than if they do not. Hence, unsurprisingly symptom severity influences help seeking.

**Illness delay** – This is the time taken between recognising symptoms as illness and deciding to seek medical attention. At this time, the individual must make a choice to either seek assistance from others like a doctor or others with a similar condition or to self-treat the illness. The move to the next step occurs when the person realises that the symptom has not disappeared either spontaneously or after self- treatment. According to Safer et al (1979) in the illness delay stage, thoughts about the symptom have the greatest impact. Thus, individuals decide to seek attention more quickly if they perceive the symptom as serious.

**Behavioural delay**- This is the time elapse between deciding to seek medical attention and the act of making an appointment. Andersen et al (1995) identify several factors that control or regulate the time between making a decision to seek professional attention and acting upon the decision. Since the research was conducted in America where people have to pay for health care, unlike the National Health Service, the first modulating factor would be response-control factors such as affordability or if it falls within insurance cover. It stands to reason that delay would be shortest for those people who have fewer concerns about the cost of treatment. This is not to say the model has no application in the UK. Although individuals do not have to pay for health care at the point of service, they may experience a loss of income because of the time spent seeking help. This may especially be a concern for those who are self-employed or whose pay is linked to production. Other moderating factors include normative factors such as family pressure and cognitive factors



like the patient's perception of their symptoms; hence delay would be shorter if the individual believed that their symptoms could be cured, for example.

**Scheduling delay-** This is the time between making an appointment and the first consultation. Scheduling delay can be due to organisational issues, for example when it is not possible to make an appointment within a certain time or personal issues when the individual cannot immediately find a convenient time to attend an appointment, for example.

**Treatment delay-** This is the time from when the person first receives medical attention and the beginning of their treatment. This type of delay is due to the availability of personnel and organisational issues (for example; waiting lists) and as such is beyond the patients' control.

Understanding delay is the all-important element; the principle aim of this study. Since studies have demonstrated that segmenting the total delay period into sequential 'periods of delay' can facilitate the search for specific causes and enhance understanding of the delay process, I charted every participants 'presentation journey' around this model of patient delay (see appendix 1 for example of first 10 interviews). This is elaborated further in chapter five and nine.

## 2.4 FACTORS RELATED TO PREDIAGNOSTIC DELAY IN MM

Even though the last decade has witnessed what can only be described as a surge in cancer related research, there remains remarkably little written about the reasons for pre-diagnostic delay in MM (Nyawata and Topping 2006). This was reinforced when

undertaking an extensive literature search using malignant (cutaneous) melanoma, presentation delay, early detection, help seeking, patient experience and diagnosis as key terms on recognised databases like MEDLINE, PubMed CINAHL, British Nursing Index, PsycINFO and hand searching key journals and cross checking citations listed in identified papers, failed to generate much research in this area. Most of the MM literature reviewed tended to focus on the cause(s) of MM (McPhail 1997; Bergenmar and Brandberg 2001; Guile and Nicholson 2004; Doherty 2005). The role of sun exposure in the pathogenesis of MM is accepted and the problems associated with sun seeking behaviour were the focus adopted in the literature. Strategies for behaviour change were therefore the major thrust of the MM related literature. Having said this, a few relevant studies that specifically investigated MM pre-diagnostic delay in terms of the factors related to it were identified and an overview of these studies is given in table 2.1.

Table 2.1 Summary Information for Selected Papers

REFERENCES (in order of publication)	AIM of STUDY	POPULATION	KEY FINDINGS/ISSUES
DiClemente et al (1982) <u>Progress in Clinical and Biological Research</u> 83,185-194.	To determine the extent of delay among patients seeking medical care for MM, whether delay influenced prognosis and what psychosocial factors influenced delay.	104 MM patients seen at a Californian teaching hospital  USA	Patient delay was a crucial factor associated with thicker lesions, higher medical risk and a poorer prognosis. 'Delayers' had substantially less knowledge of melanoma than 'non delayers'
Temoshok (1984) <u>Cancer</u> 54 (12), 3048-3053.	To investigate the relationship between patient delay in seeking medical attention and prognostic indicators, tumour characteristics, demographic and behavioural factors	106 patients with biopsy confirmed MM seen at the University of California San Francisco and Children's Hospital MM clinics  USA	Delay in seeking medical attention for suspicious lesions strongly associated with poorer prognosis. Previous knowledge, better understanding of treatment and some minimisation of the seriousness of melanoma were related to decreased delay. Lesion invisibility and nodular melanomas associated with increased delay.
Doherty & MacKie (1986) <u>British Medical Journal</u> 292, 987- 989.	To establish whether there was any evidence of inappropriate delay in receiving surgical treatment for a new or changing pigmented lesion	125 presenting to the Western Infirmary, Glasgow with MM between 1981 and 1985  SCOTLAND	Patients were responsible for delay as no evidence of delay by the hospital service was identified. Lack of knowledge found to be the main cause for delay
Cassileth et al (1988) <u>Journal of the American Academy of Dermatology</u> 18 (3), 591-598.	To investigate the sequence of events leading ultimately to the diagnosis and treatment of melanoma	275 patients attending two melanoma clinics in Philadelphia (n=130) and San Francisco (145)  USA	Components of delay were attributed both to patients (6 months) and physicians (4 months). Patients could not interpret their symptoms correctly and physicians did not always diagnose melanoma accurately. Time to diagnosis was shorter for lesions with pigmentation. Changes in colour and diameter were most commonly reported symptoms.

Rampen et al (1989) <u>European Journal of Surgical Oncology</u> 15 (2), 143- 148.	To investigate the factors involved in patients' and doctors' delay in the diagnosis and treatment of melanoma	300 consecutive patients with MM presenting with primaries or metastases registered between 1981 and 1983 in ten hospitals in Amsterdam and two in Rotterdam  NETHELANDS	The most important patients' delay factor was an unawareness of the danger of earliest signs and symptoms of melanoma. Visible melanomas were noticed quicker than those that were not visible but visibility had no impact on tumour thickness. Females had more favourable stage at diagnosis than men. Age and socio-economic status negligible.
Dunkley & Morris (1991)	To identify the reasons for delay in MM diagnosis	199 patients with a histological diagnosis of MM in the Tayside region  UK	The time to diagnosis ranged from 0- 12 months, with main components of delay being patient (0- 2months) and physician (0- 5 months). Physician delay mainly a result of mistaken diagnosis. The most commonly reported symptoms resulting in patient seeking consultation were change in size or colour and bleeding.
Krige et al (1991) <u>Cancer</u> 68, 2064- 2068.	To investigate the extent and consequence of patient and professional delay in the diagnosis and treatment of melanoma	250 patients with Stage I biopsy confirmed primary MM  SOUTH AFRICA	The major component of delay was patient related as few patients recognised early melanoma and responded to late features instead. Mean time to diagnosis 11months, with main component of delay being patient (10 months) and physician (1 month)
Blum et al (1999) <u>British Journal of Dermatology</u> 141, 783- 787.	To investigate the factors associated with the detection of cutaneous melanoma and the reasons for delay in diagnosis	429 patients with histologically proven MM  GERMANY	The 3 predominant clinical symptoms for melanoma were change in colour (darker), increase in size, and increase in elevation of a lesion. The mean delay in diagnosis was eight months. MM was more often self-detected by women than men. No association between delay in diagnosis with a) age b) gender c) tumour thickness. Melanoma awareness had no impact on the time period between first observation of change and treatment. Previous benign diagnosis by doctor lead to delays

<p>Oliveria et al (1999) <u>Journal of Clinical Epidemiology</u> 52 (11), 1111-1116.</p>	<p>To examine the relationship between patient knowledge, awareness and delay in seeking medical attention for melanoma</p>	<p>225 cases with MM identified from the Connecticut Tumour Registry that were part of a population based case-control study.</p> <p>USA</p>	<p>The mean delay was two months (0.5- 22 months). Increased knowledge/awareness of MM signs and symptoms associated with reduced delay time. Individuals who were aware of skin changes and abnormalities were less likely to delay seeking medical attention for melanoma.</p>
<p>Richard et al (2000) <u>International Journal of Cancer</u> 89 (3), 271-279.</p> <p>Richard et al (2000) <u>International Journal of Cancer</u> 89 (3), 280- 285.</p>	<p>To assess the role of patients in delays in diagnosis and melanoma prognosis</p> <p>To assess the role of doctors in delays in diagnosis and melanoma prognosis</p>	<p>590 patients with histological diagnosis of melanoma and interviewed within 12 weeks of resection, from 18 public hospital dermatology departments</p> <p>FRANCE</p> <p>As above</p>	<p>Self- detection and early presentation for help tended to be lower in older people, males, lower educated people and people living out of towns and they had greater tumour thickness. Individuals with a high number of atypical nevi, those who were aware of to be at risk and those who regularly visited a dermatologist tended to detect their melanoma more rapidly. Knowledge about melanoma was poor in many patients and wrong beliefs were widespread</p> <p>Physicians coincidentally detected 29% of melanomas, and tumour depths were lower than patient detected MM. Patients seen by dermatologist experienced shorter medical delays and lower tumour thickness than patients seen by GP. Location on acral areas and lack of pigmentation was associated with longer medical delays.</p>
<p>Brochez et al (2001) <u>European Journal of Cancer</u> 37, 843-848.</p>	<p>To investigate the diagnostic pathway for MM in order to quantify a) patient b) physician delay, and to define factors related to it.</p>	<p>130 patients from a melanoma registry in the province of East Flanders</p> <p>BELGIUM</p>	<p>The mean delay in diagnosis was 10 months – patient delay six months and physician delay 4 months. Patient delay not influenced by age, gender or socioeconomic status. Physician delay most likely involved initial misdiagnosis. The three main clinical symptoms recognised by patients were colour change, increase in size and elevation.</p>

<p>Schmid-Wendtner et al (2002) <u>Melanoma Research</u> 12, 389- 394.</p>	<p>To investigate the extent and consequence of patient and professional delay in the diagnosis and treatment of cutaneous melanoma</p>	<p>233 patients with primary MM diagnosed and treated at single centre  GERMANY</p>	<p>55% of patients waited for &gt;3 months from symptom onset to seeking medical attention. 14% waited for &gt;3months between medical consultation and excision. The predominant symptoms of melanoma detected by patients were a change in colour, and an increase in size or elevation. A delay in diagnosis and a history of outdoor activity and sunburn were not associated with a greater tumour thickness. Fairer skin, lower educational levels and lack of knowledge about melanoma were associated with greater tumour thickness</p>
<p>Montella et al (2002) <u>Preventative Medicine</u> 35, 271-277.</p>	<p>To examine the relationship between tumour thickness with diagnosis/treatment delay and sociodemographic variables</p>	<p>530 patients receiving surgery from histologically confirmed melanoma at a tertiary care facility  ITALY</p>	<p>60% of patients waited &gt;3 months from symptom onset to seeking medical attention, 31% between medical consultation and referral for hospital admission. Thicker tumours associated with a) males b) low level of education c) unemployment d) symptomatic diagnosis e) nodular melanoma f) patient delay. Lesion visibility was associated with delay</p>
<p>Betti et al (2003) <u>European Journal of Dermatology</u> 13, 183-188</p>	<p>To investigate the factors related to early detection of MM and assess the possible correlations and effects of these factors upon delay</p>	<p>216 patients with MM attending a dermatology clinic  ITALY</p>	<p>Mean delay in diagnosis was eight months, with the major component of delay being patient's lack of concern (6 months). Family members detected lesions in men more frequently, while in women self detection more common. The visibility of the tumour and socioeconomic factors did not seem to improve time to diagnosis. Suggestion of less delay in patients who were not single. Significant positive correlation between thickness and size of tumour with delay in diagnosis.</p>
<p>Carli et al (2003) <u>Archives of Dermatology</u> 139 (5), 607-612</p>	<p>To investigate patterns of detection and variables associated with early diagnosis of melanoma in a population of intermediate risk</p>	<p>816 patients with MM treated at 11 centres.  ITALY</p>	<p>40.6% self detected MM and 12.5% detected by spouse and 38.7% by doctor. Thinner tumours associated with a) females b) higher education level c) performance of SSE</p>

What is striking about the list of studies presented in Table 2.1 is the absence of contemporary literature. Some of the more robust studies identified, like the American study investigating the relationship between patient delay in seeking medical attention and prognostic indicators, tumour characteristics, demographic and behavioural factors (Temoshok 1984) and the British study that sought to establish whether there was any evidence of inappropriate delay in receiving surgical treatment for a new or changing pigmented lesion (Doherty and Mackie 1986), date back over 20 years, indicating a case for more up-to-date research given the upward trend in incidence and changing lifestyle patterns (Nyawata and Topping 2006). Added to this, since the 1980s study designs have varied in terms of methods of data collection, categorisation and analysis, making many of the papers hard to classify on the basis of methodology and comparison of results difficult. Furthermore, most of the original studies identified were not undertaken in the UK and therefore applicability to the UK might be low due to differing health care systems and lifestyles. Nevertheless, in spite of these limitations and after separating the ‘wheat from the chaff’, the search produced studies relevant to the current thesis. Three types of factors have been identified by the literature review as being related to pre-diagnostic MM delay and these will now be discussed. A fourth factor relating to psychological issues will also be discussed because it features prominently in the literature related to pre-diagnostic delay in cancer although it is less visible in MM pre-diagnostic delay.

#### 2.4.1 SOCIODEMOGRAPHIC RELATED FACTORS

Sociodemographic characteristics such as sex, ethnicity, socioeconomic status, education level and age have all been associated with presentation delay but the findings are not always consistent. An example of this inconsistency is the evidence associating age and

delay. Some studies have shown that older patients have lower rates of self detection, longer delays before seeking medical advice and greater tumour thickness (Hanrahan et al 1997; Hanrahan et al 1998; Kelly 1998; Christos et al 2000; Richard et al 2000a) and other studies have shown no association between delay in diagnosis, tumour thickness and age (Blum et al 1999; Brochez et al 2001; Baumert et al 2007). From their study examining the challenges of early diagnosis in MM Richard et al (1999) reported that older people tended to seek medical advice sooner after lesions became a 'concern'. Unfortunately this 'concern' was often triggered by late features of MM like ulceration and bleeding. Since older individuals may be less aware of skin changes, or as some have suggested, may be susceptible to a different biologic manifestation of melanoma (Hanrahan et al 1997), the impact of advancing age may influence the recognition and reporting of signs and symptoms of MM (Kelly 1998; Christos et al 2000). Hence, it maybe necessary to develop strategies specifically targeted at improving early diagnosis in older populations.

Gender appears to be one of the most powerful sociodemographic factors in predicting delay. By and large, men were found to delay more frequently than women. This delay appears to be caused by the differences in the patterns of melanoma detection and knowledge about MM between the sexes. For instance previous studies have found that women are more likely to perform skin self-examination (Berwick et al 1996; Miller et al 1996; Douglas et al 1998; Carli et al 2003) and to seek skin cancer screening (Koh et al 1991). In addition, they are more knowledgeable about the disease (Melia et al 1994; Bourke et al 1995; Miller et al 1996; Brady et al 2000). In separate investigations, Koh et al (1992), Brady et al (2000), Richard et al (2000a) and Carli et al (2003) all noted gender



differences in patterns of detection with females being more likely to discover their own lesions as well as those of their male partner. These findings were supported by Betti et al (2003) whose study of 216 melanoma patients attending a dermatology clinic in Italy found that family members detected lesions in men more frequently and despite their lack of visibility, melanomas on the backs of married men had a shorter delay than melanomas on the backs of single men as a result of their spouses detecting them. Richard et al (1999) go as far as suggesting that men simply pay little attention to their skin. Considering all these factors it is not surprising that men are reported to be more likely to present with thick primary tumours (Hersey et al 1991; Richard et al 2000a; Montella et al 2002) and consequently a poorer prognosis. This suggests the need for targeted publicity campaigns aimed at improving detection rates in men.

In several studies (Richard et al 2000a; van Durme et al 2000 Montella et al 2002; Schmid-Wendtner et al 2002; Carli et al 2003, Baumert et al 2007), delay and increased tumour thickness was associated with patients with low levels of educational attainment (no high school qualification or equivalent). In a study from Southern Italy, Montella et al (2002) reported a statistical significance between educational level and delay as well as between unemployment and thicker tumours on presentation. Patients who had less than five years of schooling, which might often lead to unemployment in the future because of poorer job prospects, were reported as having a significantly increased risk of developing a melanoma with a Breslow thickness greater than 1.5mm. Moreover, in a study from Florida, van Durme et al (2000) showed an increased percentage of melanomas at late stage (regional or distant metastases) in patients with a low educational level. These

findings become even more significant when compared to the results of other studies that have shown a higher incidence of melanoma in people with high education and high income (Harrison et al 1998; Quinn et al 2001). One may speculate that people with higher educational attainment and income have more time for outdoor leisure activities leading to intermittent sun exposure which is known as an important environmental risk factor for the development of melanoma (Armstrong 1993; Elwood and Jopson 1997). Nevertheless, despite a higher incidence of melanoma in more affluent patients, it would appear that this group seeks medical attention quicker and therefore have a high proportion of thin melanomas with favourable prognosis, unlike the patients in lower socioeconomic classes who delay and have a higher proportion of thicker melanomas.

In terms of ethnicity, research has shown that although MM is primarily a malignancy of white individuals, Black and Asians people, who are more likely to have acral lentiginous melanoma, often have extended periods of delay and advanced disease at presentation (Franke et al 2000; Cormier et al 2006). Given the atypical location of acral lentiginous melanomas (palms of the hand, soles of the feet, or under the nails), they are also often associated with longer medical delay as misdiagnosis is common (Dunkley and Morris 1991; Franke et al 2000; Richard et al 2000b). Add to this, a lack of perception of their potential risk and a lack of awareness of this disease entity in minority populations means it is not surprising that delays in diagnosis have been reported as a common occurrence in these groups.

## 2.4.2 MALIGNANT MELANOMA RELATED FACTORS

Another group of factors related to delay are those that focus on the patient's knowledge of the disease and for the purpose of this discussion these will be referred to a 'malignant melanoma related' factors. De Nooijer et al's (2001b) propose that knowledge is a necessary prerequisite for anyone to be able to interpret a symptom as a signal of cancer or judge it as serious and requiring medical attention. A literature review conducted by Nyawata and Topping (2006 see appendix 7) on the role played by symptom interpretation in presentation delay found that in almost every study, a lack of knowledge about the serious consequences of a new or growing cutaneous pigmented lesion was cited by a high percentage of those labelled as 'delayers'. In fact, studies conducted by Rampen et al (1988), Blum et al (1999), Brochez et al (2001) and Schmid-Wendtner et al (2002) reveal that the three predominant clinical symptoms of melanoma detected by patients were a change in colour (darker), increase in size and increase in elevation of a pigmented lesion. Although these are classic symptoms of early melanoma, they did not necessarily prompt individuals to seek medical intervention.

In almost every study in which patients were interviewed, a high percentage of those who delayed in seeking medical attention did not realise the seriousness or significance of their symptoms. This is supported by an oft cited American study examining the relationship between patient knowledge and awareness of melanoma with delay in seeking medical advice and prognostic outcome variables (Oliveria et al 1999). This study found that a lack of knowledge about melanoma signs and symptoms accounted for the majority of patient delay in presenting for diagnosis and treatment even though participants had visible signs

and symptoms of melanoma. As such, the literature often stresses the importance of allocating resources for educating the public to be able to recognise given signs of MM (Doherty and MacKie 1986; Krige et al 1991; Blum et al 1999; Oliveria et al 1999; Brady et al 2000; Schmid-Wendtner et al 2002; Baumert et al 2007). However, as Antonovsky and Hartman (1974 p116) eloquently put it, this orientation 'is based on the tenuous assumption of man as a predominantly rational animal'. While knowledge regarding the signs and symptoms of MM is clearly of vital importance in the early detection of cancer, a few studies that have presented a less simplistic analysis of presentation delay in MM (and other cancers for that matter) have suggested that rather than a simplistic relationship between education about cancer and delay, knowledge interacts with affective orientations towards cancer resulting in differential behaviour outcomes. In line with other classic literature (Cobb et al 1954; Goldsen et al 1957) three studies in particular, Temoshok et al (1984), Richard et al (2000a) and Ristved and Trinkaus (2005) found that knowledge about cancer symptoms, when combined with a high level of fear or anxiety resulted in greater delay. On the other hand, knowledge with a low level of anxiety resulted in less delay. In light of these arguments, it seems fair to suggest that while having adequate knowledge is necessary, indeed crucial, in being able to define a given sign as a possible symptom, it is only one step, one variable amongst others that may either facilitate or impede early detection.

### 2.4.3 HEALTH CARE SYSTEM RELATED FACTORS

The third group of factors associated with delay in MM care are those related to health care systems. A brief glance at Andersen et al's (1995 see page 61) model of patient delay places this type of delay as occurring during the fifth and sixth stage of the model-

scheduling delay and treatment delay. Most of the studies that discuss delay in the diagnosis and treatment of MM do not originate from the UK and as such illuminate problems with other health care systems that might not be transferable to the UK. An example of this are patients being unable to pay for their treatment and therefore being deterred from seeking care promptly because of the cost of health care or doctors being hesitant to refer poor patients for relatively costly specialist examinations or hospital treatments. In the UK, treatment in the National Health Service (NHS) is free to all residents at the point of need and therefore the cost of health care, which appears to be one of the greatest barriers in seeking medical assistance in other communities, does not have the same impact in deterring people from seeking medical care. However scheduling and treatment delays can still occur as there are sometimes limited facilities and specialist practitioners available to meet the sheer demand for services.

In addition, doctors, usually GPs, often add to this type of pre-diagnostic delay by sometimes misdiagnosing melanomas, especially those located on acral areas and those with a lack of pigmentation (Dunkley and Morris 1991; Richard et al 2000b; Brochez et al 2001), or by simply failing to recognise the seriousness of patients' condition. In their study of the factors associated with the detection of MM and reasons for delay in diagnosis Blum and colleagues (1999) revealed that among the factors associated with delay in diagnosing MM, an initial incorrect diagnosis as a benign lesion by the first doctor visited (usually the GP) had the highest significance. It would also appear that clinical experience in diagnosing MM correctly is related to the frequency with which melanoma and other pigmented lesions are dealt with in everyday practice. Thus patients

immediately seen by specialist dermatologists were diagnosed quicker and more accurately (Richard et al 2000b, Brochez et al 2001) when compared to patients visiting their GP. Whilst it would be impossible to expect 100% diagnostic accuracy, if the loss of valuable time is to be prevented then greater attention to MM during medical training and continuing education of the health professionals are needed, particularly for GPs (Doherty1999; Brochez et al 2001). The NHS Plan for modernising the health service in the United Kingdom first announced the creation of general practitioners with special interests (GPwSIs) in 2000 (Department of Health 2000b). These are ideally placed to improve diagnostics in MM as evidenced by the conclusions of a recent randomised control trial evaluating the GPwSI in dermatology (Salisbury et al 2005). This study found that the GPwSI service for dermatology was more accessible and preferred by patients than hospital outpatient care, achieving similar clinical outcomes.

#### 2.4.4 PSYCHOLOGICAL FACTORS

The final group of factors related to pre-diagnostic delay in cancer are the psychological factors. Numerous studies across various cancers have posited correlations between psychological traits and delays in cancer diagnosis but none were found that ventured to apply these factors in MM. By far the most commonly noted psychological barrier to seeking help in the literature is fear. A qualitative synthesis by Smith et al (2005) divides this fear into two categories; fear of embarrassment and fear of cancer. Fear of embarrassment includes fear of being labelled as a time waster or as neurotic especially for those with diverse mild symptoms, men's perception that seeking for help is unmasculine and embarrassment of sensitive or sexual areas (Gascoigne et al 1999; White and Johnson 2000; Leydon et al 2003; Chapple et al 2004). Fear of cancer includes the

fear of cancer as a fatal incurable disease. As Humphrey (1978 p. 59 cited in DiClemente et al 1982) once remarked 'fear of diagnosis of cancer is still commoner than it needs to be because the notion of incurability persists'. Thirty years on this statement still holds as more contemporary literature still cites 'fear' as one of the leading causes of delay in seeking medical assistance for cancer symptoms (Facione 1995; Gascoigne et al 1999; Burgess et al 2001; De Nooijer et al 2001a; De Nooijer et al 2001b; Chapple et al 2004; Smith et al 2005; Ristvedi and Trinkaus 2005). Although many of these studies acknowledge that 'things have changed' the fear remains nonetheless. Another fear patients frequently reported, possibly as a result of previous negative experiences of cancer, is the perception of cancer as having serious and painful symptoms that are difficult and unpleasant to treat and that often leave their 'victim' disfigured (Gascoigne et al 1999; Burgess et al 2001; de Nooijer et al 2001a; van der Molan 2000; Chapple et al 2004).

While an individual can experience a single fear, it is not uncommon to experience several of the fears together as illustrated by a study on factors affecting presentation and delay in men with testicular cancer by Gascoigne et al (1999). They found that the period following the discovery of a symptom was commonly characterised by a reluctance to seek care and several reasons for this were advanced. They included fear of a possible cancer diagnosis, castration fears (loss of sexuality), fear of embarrassment about looking foolish if nothing was wrong and about the reluctance to have the genitals examined and handled. Ironically an emotion like fear can have two dichotomous reactions. Some people may react to the fear brought about by the onset of a symptom by minimising its

seriousness, suppressing awareness of it or its possible significance and not seeking medical help, thus elongating the period of delay. Other people, prompted by the very same fears immediately seek medical reassurance that there is nothing to worry about. For health care providers the challenge is how to target those that prolong delay on this basis.

Other psychological factors that have been cited in the literature as contributing to delay include guilt, fatalism and shame, but these ideas are usually products of speculation, supposition and impression rather than evidence. Another psychological factor, denial, has also received attention in the literature as a contributory factor to delay in seeking medical treatment. Thinking on denial has come full circle, from early psychoanalytic teaching that denial was a maladaptive and immature defence to be confronted (Fenichel 1978), to later understanding denial as a common adaptive response to threat and loss that allows the individual to buy time to assimilate a painful realisation without being overwhelmed (Goldbeck 1997). Denial is a complex concept that has different meanings in different contexts and appears to serve a multitude of functions. When a person finds certain challenges too overwhelming (like the possibility of a cancer diagnosis), denial may be the coping strategy that 'works'. Denial, in this situation, provides psychological protection (Goldbeck 1997). However, the reverse side of this argument is that denying the existence of an illness or its severity causes delayed diagnosis and potentially a poorer prognosis. As such, short term delay may have some benefits but prolonged delay may have serious consequences.



The evidence presented in this chapter shows that the reasons for presentation delay in patients with signs and symptoms of melanoma are multi-factorial and influenced by a complex interaction of demographic, clinical, cognitive, behavioural and social factors. This chapter offered an analysis of these factors. Nonetheless understanding the reasons for presentation delay, though important, is not enough as early diagnosis remains highly dependent on individuals *acting* upon their signs and symptoms. Frustratingly for clinicians some individuals even when they are aware of the meaning of their symptoms fail to respond. Why people choose not to respond remains unclear and is the source of much debate and a worthy focus of further research such as this study. This chapter does not claim to provide a psychological analysis of patient's behavioural patterns but there are clearly some interesting issues that warrant further exploration and these will be explored in the next chapter.

## 3. CHAPTER THREE

### HELP SEEKING BEHAVIOUR

#### 3.1 INTRODUCTION

The study of health related behaviour has grown exponentially in the last five decades and as Scambler and Scambler (1984) observe, the published literature has become massive, detailed and disparate. Health and behaviour are related in myriad ways, yet these interactions are neither simple nor straightforward. Health-care professionals, patients, families, community leaders, and policy makers all continue to struggle not only to fully understand the interactions between health and behaviour but also how this knowledge can be used to improve the health status of individuals and populations. Given the wide acknowledgment that cigarette smoking is linked to a variety of deadly diseases, for example, why do people start smoking? And given all the recent media attention focusing on the dangers of skin cancer and convincing evidence connecting unprotected sun exposure to skin cancer, why do so many people seem to ignore these messages and continue to practice behaviours such as unprotected sun bathing and artificial UV tanning (Amir et al 2000; Bergenmar and Brandberg 2001) that put them at risk? Does such unhealthy behaviour indicate a simple lack of willpower? What processes determine that individuals persist in some behaviours, despite being aware of the risks, rather than adopting alternative forms of behaviour that would give them greater objective benefits? In the presence of symptoms, what will individuals do and why? Why do some people seek medical assistance immediately and others, perhaps with the same symptoms, do nothing? What triggers some people to seek diagnosis and treatment and what are the

barriers or challenges other people seem to face? There are no simple answers to these questions. Given all these variations in how people behave in relation to health and illness it is not surprising that many an attempt has been made to distinguish the different categories of behaviour. One of the earliest and most useful attempts was that of Kasl and Cobb (1966 p. 246) who offered the following three-fold classification and definitions:

- Health Behaviour is any activity undertaken by a person believing himself to be healthy for the purpose of preventing disease or detecting it in an asymptomatic stage
- Illness behaviour is any activity, undertaken by a person who feels ill, to define the state of his health and to discover a suitable remedy. The principal activities here are complaining and seeking consultation from relatives, friends and from those trained in matters of health.
- Sick Role behaviour is the activity undertaken by those who consider themselves ill, for the purpose of getting well. It includes receiving treatment from appropriate therapists, generally involves a whole range of dependent behaviours and leads to some degree of neglect of one's usual duties.

Although health and sick role behaviour will be considered to add richness to the texture of the chapter, this chapter will largely focus on illness behaviour because it is during this phase that individuals begin their journey to specialist care and the processes involved in seeking help are very important to this thesis. In order to understand presentation delay in MM sufferers it is crucial to locate where it occurs along the disease trajectory. In the first part of this chapter health, illness and sick role behaviour are discussed in greater depth.

The second and bigger part, introduces two approaches to studying illness behaviour namely psychology and sociology and gives a few examples of models and theory generated by these two approaches and how they influence illness behaviour in general and more specifically the process of seeking medical help. The final part of the chapter focuses on lay referral systems and social networks and the role they play in help seeking.

### 3.1.1 HEALTH BEHAVIOUR

Health behaviour involves any activity people perform to maintain or improve their health, regardless of their perceived health status or whether the behaviour actually achieves the goal (Sarafino 2006). A similar definition offered by Harris and Guten (1979), states that health behaviour involves actions undertaken by an individual, regardless of their actual or perceived health status, for the purpose of promoting, protecting or maintaining health, whether or not such behaviour is objectively effective towards that end. According to these definitions, health behaviour includes both preventative and health promoting activities. Promoting positive health behaviour is a national drive in health policy. For many years healthcare policy in Britain has been moving away from an emphasis on curative medicine towards a focus on prevention. The knowledge that unhealthy personal lifestyle choices account for a large proportion of both morbidity and mortality in the UK (Naidoo and Wills 2000) and the subsequent cost of these choices to society have been the impetus of numerous policy documents and government reports over the years. A white paper published by the Labour Government in the mid 1970s entitled Prevention and Health categorically stated that:

*Much ill-health in Britain today arises from overindulgence and unwise behaviour...the individual can do much to help himself, his family and the community by accepting more direct responsibility for his own health and well being*

(Department of Health and Social Security 1976)

Ten years later a White Paper entitled Promoting Better Health (Department of Health and Social Security 1987) published under the Conservative Government presented a similar view and described major health problems such as heart disease and cancer as ‘lifestyle based’. More recently the Government’s public health White Papers Saving Lives: Our Healthier Nation (1999) and Choosing Health: Making Healthy Choices Easier (2004) identify and target health compromising behaviours such as cigarette smoking, excessive alcohol consumption, other substance abuse, unhealthy dietary habits, sun exposure, sedentary lifestyles, and non-adherence to effective medication regimens for modification or prevention with consequent benefit to the public health. The clear message coming from these publications is that individuals should take responsibility for their own health and the health of others. Many health problems are considered to be behavioural in origin and therefore preventable. Individuals are encouraged to make the ‘right’ choices and take steps to protect and improve their own health.

The health behaviour initiative is an important component of cancer care. In the context of MM, personal choices made with regard to sun exposure or sun screen use can have a powerful impact on primary prevention. In addition personal decisions about learning and performing routine self skin examination (SSE), participating in skin cancer screening activities and seeking appropriate help when cancer signs and symptoms are noted are

pivotal to the early detection and potential cure of MM. Also, behaviour with regard to following a recommended treatment regime and maintaining a healthful lifestyle while experiencing or undergoing treatment for cancer may enhance both quality and quantity of life. Consequently, individual health behaviour should be an important consideration for health professionals who interact with people at any phase of the cancer continuum.

### 3.1.2 ILLNESS BEHAVIOUR

The term 'illness behaviour' was coined by Mechanic and Volkart in 1961 to describe the 'way in which symptoms are perceived, evaluated and acted upon by a person who recognises some pain, discomfort or other signs of organic malfunction'. It refers to the various ways individuals respond to 'bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilise various sources of informal and formal care'(Mechanic 1995 p.1208). In other words, the basic problem to be considered when studying illness behaviour is; in the presence of symptoms what will the individual do and why do they do it? (Kasl and Cobb 1966). The answer to this question is particularly relevant to this thesis. The fact that health professionals only come into contact with the tip of an 'illness iceberg' is now well established (Last 1963; Scambler and Scambler 1984; Harding and Taylor 2002). Most symptoms do not lead to a medical consultation. A study conducted by the British Market Research Bureau (1997) of over 1000 adults in Britain found that 91 per cent had experienced at least one ailment during the previous two-week period (average = 5.2 ailments). Just under half (46 per cent) dealt with their symptoms by taking no action, 32 per cent used over-the-counter products or previously prescribed medication and 9 per cent used a home remedy, such as a hot-water bottle. Only 11 per cent sought medical advice from a doctor, dentist or

pharmacist. It would be reasonable to assume that those symptoms untreated by a medical professional were mild, unobtrusive and were not indicative of conditions or diseases requiring medical attention. On the other hand research into GP caseloads has revealed that the majority of consultations are concerned with minor disorders or the 'worried well' (Wyke et al 1998). Furthermore, other studies have shown that GPs are often not consulted about many conditions that would respond to treatment. This gives a clear indication that predicting what people will do in the presence of a symptom is not always possible and consequently seeking medical assistance is by no means a simple clear cut process. It would seem that a myriad of factors influence the illness behaviour that individuals engage in once they perceive themselves to have a health problem. Although functionalists like Parsons (1951) consider that faced with illness, the socially responsible individual is expected to consult medical opinion, sociologists working from an interactionist viewpoint suggest that on the contrary, seeking medical attention may well be the last resort once other avenues of advice and assistance have been exhausted.

In his classic analysis of the route from 'person to patient' Zola (1973) provides an illustration of the complexities involved in illness behaviour. He contends that the decision to go to the doctor- how and why an individual seeks medical assistance- is by no means as obvious as one might like to think. There is a popular assumption that rational individuals respond to clear, infrequent and therefore somewhat dramatic symptoms by seeking appropriate medical help. When this does not happen or individuals delay they are often labelled as irrational. Zola (1973) considered the nature of illness and argued that since humans are subject to a vast array of bodily discomforts virtually everyday of their

lives, and only an infinitesimal amount of these get to the doctor then ‘something critical’ must ordinarily happen to make an individual seek help. From the results of his study of patients new to outpatient clinics at Massachusetts General Hospital and seeking medical help for the first time, he came to the conclusion that individuals often have symptoms for a long time before seeking help and there is a kind of normalising, an accommodation physically, personally and socially of their symptoms. It is only when this accommodation breaks down that an individual seeks help. What causes this accommodation to break down is the development of ‘non physiological patterns of triggers to the decision to seek medical aid’. From the data Zola (1973) identifies five such ‘patterns of triggers’ namely the occurrence of an interpersonal crisis, the perceived interference with social or personal relations, sanctioning by a significant other, the perceived interference with vocational or physical activity and temporalising of symptoms. Whether these ‘patterns of triggers’ can be applied to MM care will be discussed later in the thesis.

### 3.1.3 SICK ROLE BEHAVIOUR

The sick role, postulated by Talcott Parsons (1951) is a form of behaviour deemed appropriate to those encumbered by illness. It is a temporary state, to which entry and exit is legitimised by the medical profession using objective, scientific criteria to define and treat illness. Taking on a sick role benefits individuals in two ways. First, they are able to gain exemption from their normal roles, such as employment or domestic work (often sanctioned by a doctor’s sick note) and second, they are not held responsible for their illness. However in return for these benefits, patients are expected to fulfil two obligations. First, they should recognise that the sick role is only a temporary state that they must want to leave, in other words, they must want to get well and second, they must



cooperate with competent health professionals, by complying with medication regimens for instance.

The sick role and sick-role behaviour can be seen as the logical extension of illness behaviour to complete integration into the medical care system. Parson's (1951) argument is that sick-role behaviour accepts the symptomatology and diagnosis of the established medical care system, and thus allows the individual to take on behaviours compliant with the expectations of the medical system. However, the sick role concept has some shortcomings. For instance, the model assumes that individuals will voluntarily accept the sick role and take on the 'passive patient' role. However, they may not always comply with the expectations of the 'role' by not giving up social obligations, may resist dependence and if the illness carries a stigma may avoid public sick role behaviour altogether. Added to this, the model has also been criticised because it is mostly applicable to acute illness and does not fit chronic, long term or permanent illness as easily since complete recovery is not always possible in these conditions and chronically ill patients are often encouraged to be independent (Harding and Taylor 2002; Young 2004). Nevertheless, as a theoretical model, the sick role recognises that sickness is not a passive biological state, but an active social role. Moreover, because the model assumes 'ideal' patient and doctor roles, it does not necessarily correspond with empirical reality, but provides a device against which actual illness behaviour and experience can be assessed (Nettleton 1995).

### 3.2 APPROACHES TO STUDYING ILLNESS BEHAVIOUR

Presenting some thoughts on studying illness behaviour, David Mechanic, a pioneer in the study of illness behaviour, offers the following insights: 'Illness behaviours arise from complex causes, including biological predispositions, the nature of symptomatology, learned patterns of response, attributional predispositions, situational influences, and the organisation and incentives characteristic of the health care system that affect access, responsiveness and the availability of secondary benefits' (Mechanic 1995 p.1213). In his view, illness behaviour has socio-cultural and psychological components and as such the traditional bio-physiological approach of the medical profession to sickness is inadequate to describe the complexity of illness behaviour. Young (2004) points out that since doctors view illness as disease, a biological process that can be categorised and treated, they often ignore the social aspects of illness and distinctions between illness and disease. Illness is a socially defined concept, the subjective interpretation of problems that are perceived as health related (Scambler and Scambler 1984; Harding and Taylor 2002). Disease and illness do not stand in a one to one relationship. As such, to view patient help seeking behaviour merely as a response to the symptoms caused by disease is simplistic.

In their seminal paper Kasl and Cobb (1966) suggested that in addition to the physical symptoms traditionally accepted by medicine as the cause for seeking help, there are social and psychological forces that also play a part. While there are several other approaches or orientations to studying illness behaviour (McKinley in 1972 identified six), this chapter will only focus on two of the most frequently used orientations- psychology and sociology. The main difference between these two orientations is that the

psychological component of illness behaviour tends to be individualistic and focuses on the mental processes involved in perceiving, evaluating and acting upon symptoms whereas the sociological aspects of illness behaviour focus on the role played by social relationships, social interaction and culture on illness behaviour. The next few paragraphs will give examples of how both orientations influence illness behaviour beginning with the psychological approach.

### 3.2.1 THE HEALTH BELIEF MODEL

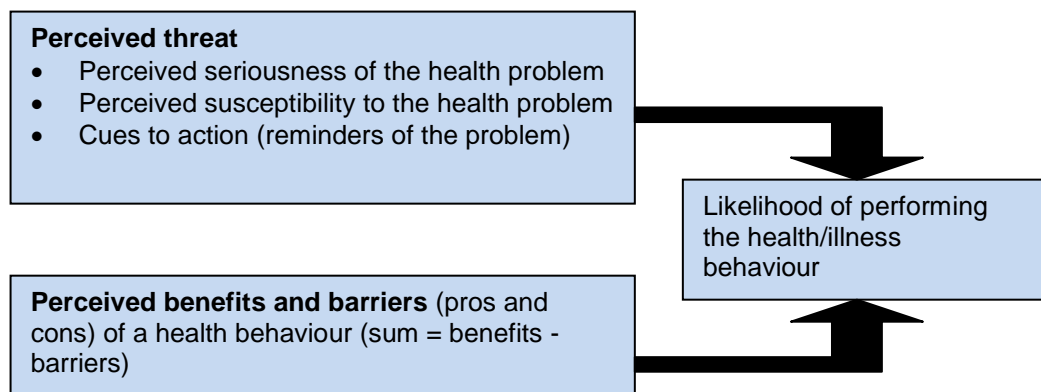


Figure 3.1 The Health Belief Model

Though several models have been proposed by the psychological school, paramount amongst them has been the Health Belief Model (Rosenstock 1966; Becker 1979; Becker and Rosenstock 1984). Like all models the Health Belief Model (HBM) has its shortcomings but by virtue of its having exerted such a huge influence on the field, a review of it in the context of melanoma care will provide the reader with a sufficient basis for evaluating how well models of this genre can be applied to understanding and predicting help seeking behaviours.

The Health Belief Model (HBM) is a psychological model that attempts to explain and predict health behaviours. This is done by focusing on the attitudes and beliefs of individuals. It was first developed in the 1950s by social psychologists Hochbaum, Rosenstock and Kegels working in the United States Public Health Services. The model was developed in response to the failure of a free tuberculosis (TB) health screening program (Rosenstock 1966; Pender and Pender 1996) and emerged to explain and help others understand why people failed to participate in disease prevention strategies or asymptomatic screening or failed to comply with or adhere to medical advice or regimes (Topping 2005). According to the Health Belief Model (HBM), the likelihood that a person will take action, that is, perform some health or illness behaviour depends directly on the outcome of two assessments they make. Figure 3.1 shows that one assessment pertains to the threat the person feels regarding a health problem and the other weighs the pros and cons of taking the action. Three factors influence people's perceived threat - that is, the degree to which they feel threatened or worried by the prospect of a particular health problem:

- **Perceived seriousness** of the health problem. People consider how severe the organic and social consequences are likely to be if they develop the problem or leave it untreated. The more serious they believe its effects will be, the more likely they are to perceive it as a threat and take preventive action.
- **Perceived susceptibility** to the health problem. People evaluate the likelihood of their developing the problem. The more risk they perceive for themselves, the more likely they are to perceive it as a threat and take action.

- **Cues to action** Being reminded or alerted about a potential health problem increases the likelihood of perceiving a threat and taking action. Cues to action can take many forms, such as information from the mass media describing cancer symptoms, a friend or relative developing an illness, a newspaper article about the illness, or a reminder phone call or letter for an upcoming medical appointment (Sarafino 2006).

In weighing the pros and cons of performing certain behaviours, people assess the benefits and the barriers or costs they perceive in taking action.

In MM care what barriers might people see? For the health behaviour of reducing exposure to the sun, the barriers might include psychosocial consequences ('People always tell me I look better with a tan'), and for the illness behaviour of seeking medical assistance promptly, the barriers might include physical considerations ('The medical centre is on the other side of town and I don't have a car'). The outcome of weighing the benefits against the barriers is an assessed sum: the extent to which taking the action is more beneficial for them than not taking the action (Sarafino 2006). In their study of the use of sunscreen by health care professionals Grubbs and Tabano's (2000) findings supported the HBM's explanation of health-related behaviour. Participants at high risk of developing skin cancer (assessed by personal and family history of skin cancer, natural skin, eye and hair colour, tendency to burn, number of sunburns before the age of 20, number of sunburns that blistered or peeled, frequency of sunscreen use and sun beds use) reported an appropriate level of high perceived susceptibility and 65% of them used sunscreen at least 75% of the time. The research concluded that in line with the HBM,

people who felt threatened by skin cancer and believed that the benefits of protecting themselves from the sun outweighed the barriers (getting skin cancer) are likely to go ahead with. On the other hand, those health care professionals at low risk of developing skin cancer reported a low perceived susceptibility and as such did not make a great effort to reduce their unprotected exposure to the sun.

The HBM also proposes that characteristics of individuals can influence their perceptions of benefits, barriers, and threat. These factors include the person's age, sex, race, ethnic background, social class, personality traits, and knowledge about or prior contact with the health problem. Thus, anecdotally women, but not men over 50 are likely to perceive a substantial risk of breast cancer and elderly individuals whose close friends have developed severe cases of cancer or heart disease might be more likely to perceive a personal threat of these illnesses than young adults whose friends are in good health (Sarafino 2006). More specifically, as discussed above in the demographic variables relating to MM presentation delay (section 1.4.3), Black and Asian people who generally do not perceive themselves to be at risk of MM are unlikely to present quickly for medical assistance, men who often perceive many barriers to seeking medical assistance (Addis and Mahalik 2003) are less likely to present for medical assistance than women who generally perceive seeking medical help as beneficial (Corney 1990; Macintyre et al 1999), people of lower socio-economic classes are likely to have less knowledge of the dangers of MM and therefore have a lower perception of the seriousness of their condition and do not seek help (Baade et al 2006) and the elderly, who respond to cues for action are

more likely to seek medical advice sooner after lesions become a concern (Richard et al 1999).

The preceding section, has examined aspects of people's beliefs and perceptions that appear to influence their behaviour. These aspects include their perceived susceptibility to illness, perceived seriousness of a health problem and perceived barriers and benefits to taking action. These factors seem sensible for individuals to consider, but what if the decisions they go on to make are unwise, even irrational? The major downfall of the HBM is that it views individuals as rational decision makers, systematically reviewing available information and behaving accordingly. It does not account for those people who seem to make irrational decisions or provide an understanding of how people make decisions. Like other social cognitive models, the HBM has been criticised for being divorced from the social context in which people live their lives (Topping 2005). An example of this is the fact that even though the negative effects of being over exposed to the sun are well documented (McPhail 1997; Bergenmar and Brandberg 2001; Guile and Nicholson 2004), society still perceives tanned skin as attractive, illustrating the tension between 'looking' healthy and actually behaving in a healthy manner.

The flawed decisions that people make about their health often result from motivational and emotional processes that are not addressed in theories like the HBM. For instance, this theory does not provide an adequate explanation for the widespread tendency of patients to delay seeking medical help when they are aware of symptoms such as severe chest pain during a heart attack (Johnson et al 1995) or they can observe a growing lesion in

malignant melanoma or a lump in their breast in breast cancer. It would almost seem that afflicted individuals sometimes sabotage themselves by refusing to take action when symptoms seem so 'obvious'. Clearly, theories that focus on rational thinking do not adequately illustrate why individuals do the things they do and are therefore inherently flawed. These problems do not mean that these theories are wrong because they do provide valid explanations for parts of the process that determines people's practice of illness related behaviour- they are just incomplete. In order to complete the picture Sarafino (2006) suggests that other 'less rational' psychological processes such as motivational and emotional factors can override logical decision making.

### 3.2.2 MOTIVATIONAL AND EMOTIONAL FACTORS

When considering a person's illness behaviour the question that is often asked is: 'Why did they do that?' This question obviously occupies an important place in the study of behaviour. The permutations to this question are almost infinite but according to Oliver (2003) lead to the all embracing subject of motivation and emotion. A motivation is a condition that energises behaviour and gives it direction (Smith et al 2003) and in its most general definition, an emotion is a complex psychophysical process that arises spontaneously, rather than through conscious effort, and evokes either a positive or negative psychological response (Bernstein et al 1991). Emotions are often related to feelings, perceptions or beliefs (Smith et al 2003). Motivation and emotion are closely related. Both depend on the relationship between the individual and their environment. In the case of emotion, the emphasis is on the evaluative aspect of this relationship; how the situation makes the person feel and in the case of motivation, it is how the individual acts with respect to the situation that is of interest (Kuhl 1986). There are obvious links between



emotion and motivation, because situational evaluations largely determine action priorities (Parkinson and Colman 1995). In other words, how we feel about something often determines how we act. In the context of seeking medical care for symptoms it can be said how an individual feels about a particular symptom(s) will determine how they act. Thus it can be argued that if an individual does not *feel* threatened or alarmed by their symptoms then they are unlikely to seek medical attention for them. Emotion is generally regarded by Western civilization as the antithesis of reason (Smith et al 2003) and therefore feelings do not always reflect the reality of the situation. For example, an aggressive vertical growing melanoma may present as what appears to be an innocuous lesion. The patient may actually be aware of it but because of its appearance does not feel worried or concerned. In reality the patient is in danger of the melanoma metastasising but their perceptions do not reflect the gravity of the situation.

Motivation encompasses a range of interlocking processes, including biologically defined urges and desires, acquired affinities and aversions, and the implementation of conscious intentions. A complete explanation of any motivational phenomenon always includes reference to an interaction of both internal and external factors, and to instinct as well as learning (Parkinson and Colman 1995). In the same vein, emotion is a very complicated, multifaceted phenomenon and its essential qualities are not easily defined although some have attempted to do this with the use of models and theories. In spite of the fact that the approaches to examining motivation and emotion are many and varied, studying them in detail is beyond the scope of this thesis and as such only a synopsis of how these ‘less

rational' psychological processes (Sarafino 2006) influence illness behaviour has been given.

### 3.2.3 PERSONALITY

No discussion about illness behaviour would be complete without discussing the role of personality. Personality can be defined as a dynamic and organised set of characteristics possessed by a person that uniquely influences his or her cognitions, motivations, and behaviours in various situations (Ryckman 2004). Coming to terms with human individuality and what makes an individual personality is one of the most fascinating questions in psychology and throughout the centuries personality has been described and measured by a range of theories and models. Today there are four main approaches to personality namely the psychodynamic, the dispositional, the behavioural and the humanistic and these will now be discussed briefly.

The psychodynamic approach founded by Freud seeks to explain the dynamics of personality as a whole. Personality is formed out of conflicts between basic needs and the demands of the real world. Most of these conflicts occur at an unconscious level but their effects can be seen in everyday behaviour (Bernstein et al 1991; Hayes 1998; Engler 2006). Besides the psychodynamic approach to personality there are more descriptive ones. The dispositional personality perspective depicts personality as made up by physiologically based traits, which guide behaviour. Traits can be described as tendencies to behave and react in a specific way (Phares and Chaplin 1997). The third approach to personality is the behaviourist approach. This perspective emphasises the importance of environmental or situational determinants of behaviour. In this view, behaviour is the

result of a continuous interaction between personal and environmental variables. Environmental conditions shape behaviour through learning and a person's behaviour, in turn shapes the environment (Smith 2003; Ryckman 2004). In other words people and situations influence each other and according to Bandura (2001) in order to predict a person's behaviour, how their characteristics interact with those of the situation must be known. The final approach to personality is the humanistic approach (also called the phenomenological approach) and it is based on the assumption that personality is determined by the unique ways in which each individual views the world. These perceptions form a personal version of reality and guide behaviour as people strive to reach their fullest human potential (Bernstein et al 1991; Ryckman 2004; Engler 2006). After 50 years of personality research there is a common agreement in the field that there are five basic dimensions that can be used to describe differences in cognitive, affective and social behaviour. This is the base for the five-factor model of personality. In this model personality is described in terms of five broad traits, generally denoted with the terms extroversion, agreeableness, conscientiousness, neuroticism and openness to experience (Costa and McCrae 1992; Pervin 1994)

Whatever approach to personality one chooses to subscribe to there is a clear thread that runs through them all; personality influences behaviour. Unfortunately, there are hardly any studies examining the relationship between personality and illness behaviour and the literature on illness behaviour seldom discusses the effects of personality on how individuals perceive their health. Still, there are good reasons to expect that personality affects how people perceive, evaluate and act upon their symptoms. For instance,

personality is related to some people's tendency to worry about their health (Costa and McCrae 1992) and the inclination to seek medical help for their symptoms whereas other people do not seem particularly bothered about their health and have a correspondingly nonchalant attitude about seeking medical help. Indeed, one study demonstrated that certain personality types tend to predict higher perceived susceptibility to negative life events such as ill health whereas other personalities tend to be more optimistic and do not have the same negative expectations of ill health and would therefore react differently to very similar symptoms (Darvill and Johnson 1991).

In 1968, Walter Mischel challenged the assumption that personality determined behaviour and instead claimed that people's behaviour from situation to situation was variable and depended on the situational circumstances. In other words, the 'situation' view is that behaviour depends on the situation itself, whereas the personality view is that behaviour depends on long-held characteristic personality styles and is consistently displayed no matter the situation. Although such absolute views has been repeatedly challenged over the years by those on the side of personality (Contrada and Goyal 2005) there is some truth in the opinions expressed because while personality influences behaviour one can not deny the fact that different situations affect different people in different ways. In light of these observations it seems reasonable to conclude that personality traits and situations interact to influence behaviour. One cannot exist without the other. To put it simply

$$\text{Behaviour} = \text{personality} \times \text{interpretation of the situation}$$

Research has shown that personality is a strong predictor of behaviour across all situations, that is, of an individual's overall trends, but is not a strong predictor of their behaviour at a specific time in a specific situation (Kenrick and Funder 1991). Thus

personality more accurately predicts someone's general help seeking behaviour than it would predict their reaction to a specific symptom. In order to link all psychological determinants of help seeking behaviour discussed in this chapter, the little equation presented above can be applied as follows: whether an individual will seek medical assistance for their MM symptoms (their behaviour) is determined by their personality and how they interpret the situation. How they interpret the situation is determined by whether they feel threatened by the symptoms (Health Belief Model) and how they *feel* about their symptoms (motivational and emotional factors).

#### 3.2.4 SOCIAL NETWORKS IN ILLNESS BEHAVIOUR

Having considered illness behaviour from an individualistic psychological perspective the chapter will now move on to discuss illness behaviour from a sociological viewpoint, which according to Scambler and Scambler (1984) tends to be 'collectively oriented' as emphasis is placed on the notion that patterns of behaviour appropriate to specific situations are 'learned' through socialisation into particular cultures and subcultures. Sociological approaches to the study of illness behaviour have generated theoretical models that emphasise the fact that notions of, and responses to, illness are shaped by social and cultural factors (Clarke 2001). These models concentrate on how individuals come to a point where they define themselves as ill and how they respond to the problematic experience of illness. It has been suggested by some that the significance of symptoms is not always immediately self evident. The individual does not react to the symptom itself but to the meaning attributed to the symptom (Freidson 1970; Zola 1973; Clarke 2001; Gabe et al 2004). In attributing meaning to an illness experience 'the individual sufferer does not invent the meanings himself but rather uses the meanings and

interpretations that his social life has provided him' (Freidson, 1970 pg. 288). In Freidson's view it is lay culture that creates 'illness' as a social meaning. If an individual perceives themselves to be in need of medical help because they are ill and can show evidence of the symptoms that others in their cultural milieu believe to be illness and interpret them in a way the others find plausible, then they are likely to find agreement and support from their peers (Freidson 1970; Scambler and Scambler 1984).

Some researchers have examined the sociological approaches to the study of illness behaviour by paying particular attention to the strength of social network ties and the relative importance of kinship and friendship networks. Social networks are defined as 'social relationships a person has during day-to-day interaction that serve as the normal avenue for the exchange of opinions, information, and affection' (Cockerham 2000 p118). These networks include family, friends and co-workers - the local social world of the individual. The focus on social networks in illness behaviour offers an alternative to the individual focus of psychological theories and models and social network analysis has become an important analytic tool for studying the impact of family, friends and lay others on the process of seeking medical care (McKinlay 1972; Pescosolido 1992; Nettleton 1995; Clarke 2001; Young 2004). According to social network theory people do not function in society solely as individuals, but also as members of interpersonal and organisational networks. These networks are their social capital (Wellman and Wortley 1990) and provide them with resources to cope with routine and extraordinary circumstances and links to others who may be of use. In this sense, authors like McKinlay (1973) and Suchman (1965) argue that they are an important connection between the 'pre-patient' and

medical worlds because people close to the potential patient channel behaviour and may impede or facilitate access to care. How family, friends and significant others' perceive the process of seeking medical help and their attitudes towards health care will affect an individual's help seeking behaviour. In fact, according to McKinlay (1973) under-utilisation of services may be related to strong social networks that take a negative view of organised health care. Levy (1983) outlines the following mechanisms by which social networks affect care:

- directly modulated by family and friends
- transmitted beliefs through the socialisation process
- healthy and unhealthy behaviours reinforced by activities, verbal stimuli and example
- reduced social support or increased social impediments to care

Using help seeking behaviour as her empirical and theoretical example, Pescosolido's (1992 p 1113) influential article found that people have social networks that serve the decision making process on the issue of help seeking as a 'therapy management group'. This group modulates access to care, satisfaction with care and the success of the treatment. Thus social networks influence illness behaviour and form a middle tier between the individual and formal health care systems. Indeed, Kleinman (1980) argues that this 'popular sphere' (members of one's community) of health care is the largest part of any system and the most poorly understood; he estimates that 70-90% of all illness episodes are initially managed within the lay sector by social networks and joined by Pescosolido (1992) argues that social networks should be the focus of more health research.

### 3.2.5 FRIEDSON AND LAY REFERRAL SYSTEMS

As the previous section has established, from a sociological point of view illness behaviour needs to be considered within a wider socio-cultural framework (Clarke 2001) since becoming ill is a social process that involves other people beside the patient. Zola (1973) maintains that the decision to consult a doctor is not simply based on how the patient interprets the symptoms but is also influenced by how relatives, friends and work colleagues perceive the problem. Friedson (1970) uses the concept of the 'lay referral system' to explain help seeking behaviour. The lay referral system has two components: a 'lay culture' which may be more or less congruent with that of the medical profession and a 'lay referral structure' which refers to the social network of personal contacts that may influence the individual in deciding what action to take regarding a particular symptom episode (Clarke 2001). Freidson (1970) gives a more systematic account of this process of seeking help explaining that 'the whole process of seeking help involves a network of potential consultants, from the intimate and informal confines of the nuclear family through successively more select, distant, and authoritative laymen, until the 'professional' is reached. This network of consultants, which is part of the structure of the local lay community and which imposes form on the seeking of help, might be called the 'lay referral structure'. Taken together with the cultural understandings involved in the process, we may speak of it as the 'lay referral system'" (Freidson 1970 pg 377).

Zola (1973) found lay referral to be one of the key 'triggers' or precipitants of medical consultations, a phenomenon he called 'sanctioning' (see section 3.1.2). These lay referral systems have been found by social scientists across cultures and social classes (Polgar



1962, Suchman 1965, McKinlay 1973; Scambler et al 1981) and generally follow the following steps:

1. Self-diagnosis, which often leads to negative action as the ill person decides there is nothing really wrong and that he will wait and see what happens.
2. Self-medication, which often but not always follows self-diagnosis. Self-medication takes many forms such as over the counter medications, home remedies, alternative therapies, prayers and even incantations.
3. Lay consultation through a hierarchy of authority often beginning with spouses, then other members of the household, then relatives and friends.
4. The lay referral system becomes more selective, purposeful and authoritative as others like another layman who himself had and cured the same symptoms, or someone who was once a nurse therefore knows about such things are consulted.
5. The doctor (or any other professional who is considered appropriate such as the dentist or pharmacist) is reached.

Polgar (1962) sees an intermediate type of consultation in literate societies prior to reaching the professional which involves reference to manuals on health care, religious texts, the 'Dear Doctor' column in the newspaper and articles in popular magazines. In recent times this type of consultation would no doubt include the internet.

This chapter has reviewed much of the seminal illness behaviour literature. It can be argued that some of the studies reviewed are dated but their strong influence over subsequent work is undeniable. Even though innumerable health related behaviour studies have been conducted since, most still refer to original works such as Parsons (1951),

Mechanic and Volkart (1961), Kasl and Cobb (1966), Freidson 1970 and Zola (1973) and as such this seminal work is still applicable. The major focus of this chapter has been illness behaviours; what individuals do in the presence of symptoms and why do they do it. Illness behaviours arise from complex causes (Mechanic 1995) and although there are numerous possible approaches to studying them, this chapter focused on two of the most frequently used, psychology and sociology. Examples of how the psychological approach influences illness behaviour included the HBM, which states that the likelihood that a person will perform some illness behaviour depends on their perception of threat and the perceived benefits of taking the action. Other psychological influences discussed included motivational and emotional factors and personality. Deliberations of the influences of sociology on illness behaviour focused on social network systems and lay referral systems.

Whilst discussions on psychological and sociological influences are useful tools in describing the processes involved in illness behaviour and offering an explanation of why people do the things they do, they still do not elucidate fully what is happening within the process. It is unlikely that any model, theory or concept has the capacity to offer a universal explanation for why individuals choose to behave in certain ways, in this case decide not to seek medical assistance for their MM symptoms, because all individuals are different and a 'one model fits all' approach can not be applied. These models and theories are just tools, guidelines and strategies and as highlighted by Naidoo and Wills (2000) not only do they provide health professionals with a better understanding of their patients' behaviour they can also be helpful in encouraging them to think theoretically and come up

with new strategies and ways of working that help them to achieve their goal of patient centred care.

PART TWO

**METHODOLOGY AND DESIGN**

## 4. CHAPTER FOUR

### PHILOSOPHY OF RESEARCH

#### 4.1 INTRODUCTION

As was discussed in the introduction of this thesis the impetus for this research project arose from observations made in clinical practice. A cursory glance at the literature indicates that across a wide range of illnesses including cancer, the prognosis is almost always more favourable when an individual presents for detection and treatment early in the disease trajectory. In spite of this evidence some patients still present for help and diagnosis when their condition is at an advanced stage and this research has endeavoured to understand why this is so. The review of the literature presented in Part One of this thesis reveals the paucity of literature related to presentation delay in MM and what literature there is tends to be quantitative in nature. Whilst these studies provide statistical evidence that has established that presentation delay in MM patients is a feature of the clinical presentation of some individuals, this work has failed to explore in any great depth why this occurs. In order to better understand why people delay so as to identify how earlier presentation in MM patients might be encouraged it seemed timely to examine the experiences of patients from their perspective. While some researchers view quantitative and qualitative as ‘opposing’ or ‘competing’ methodologies for the ways in which social reality should be studied (Hammersley and Atkinson 1995), this need not be the case. Although they are different, they can often be used to complement each other (Topping 2006). From the nature of the research question; ‘what are the challenges, if any, that individuals subsequently diagnosed with malignant melanoma face that impede or

facilitate their presentation for diagnosis and treatment?’ it became apparent that a qualitative approach would be more appropriate - not in opposition or rivalry to existing research evidence but to complement it and add further texture to understandings about presentation delay in MM.

Before the emergence of modern research, philosophers had long referred to research as logical reasoning (Trochim 2006). Therefore, it should not come as a surprise that some philosophical tenets have carried over into contemporary research. Many have suggested that it is not possible to conduct rigorous research without trying to understand its philosophical underpinnings (Gray 2004; Silverman 2005; Topping 2006). This is because all research is based on assumptions about how the world is perceived and how we can best come to understand it. The purpose of this chapter is to explore the philosophical underpinnings of this research project in order to justify the qualitative approach chosen. According to Crossan (2003) the ongoing ‘quantitative/qualitative’ debate is fogged by lack of coherent definitions and by a focus on methods rather than an exploration of underlying philosophy- something this chapter seeks to rectify. The first part gives an outline of the study’s philosophical approach and links the ontological and epistemological perspectives of the study with the chosen qualitative methodology; grounded theory. The second part of the chapter discusses the philosophical underpinnings of constructivist grounded theory. Finally the chapter introduces the idea of rigour with reference to how the quality of the various conclusions that are reached in the study will be appraised.

## 4.2 THE PHILOSOPHICAL APPROACH

According to Proctor (1998) and Gray (2004) consistency between the aim of a research study, the research questions, the chosen methodology and methods, and the personal philosophy of the researcher is the essential underpinning and rationale for any research project. They assert that before any decisions on how the research will be conducted are made, it is useful for the researcher to clarify any assumptions related to their personal values. Proctor (1998) concedes that although individuals rarely take time to do this in everyday life, exploring basic personal beliefs could assist researchers in understanding wider philosophical issues, such as ‘the interrelationship between ontological (what is the nature of reality?), epistemological (the nature of knowledge and what is understood to be reality; what can be known?), and methodological (how can a researcher discover what they believe can be known?) levels of enquiry’

The ontological position taken in this study is relativist. This is based on the premise that social reality is made up of individual and shared meanings, interpretations, attitudes and beliefs (Mason 2002). The ‘reality’ of the social world, therefore, is socially constructed and exists as different things to different people. Attaining one true reality is not the objective of the relativist stance thus it frees the researcher to present rigorously obtained data from various perspectives, including their own, without the burden of determining that only one perspective is the truth. My experience as a nurse with a dermatology background and the patients’ experiences become interactively linked so that the findings were literally created and constructed as the investigation proceeded. On the basis that the research ontology is relative, the epistemological position adopted for this study is

subjective in nature because it relies on individual accounts of subjective meaning and experience (Guba and Lincoln 2004; Silverman 2005). ‘Truth’, therefore, is the triangulation or combination of multiple perspectives that have been constructed by different individuals based on their perceptions of the world.

Epistemology bears heavily on the ways research is done and Easterby-Smith et al (1991) argue that it is important to articulate the epistemological perspective adopted because it helps to clarify and position the research design, assists in determining the kind of evidence gathered, who and where it is gathered from and how it will be interpreted. There are two extreme epistemological positions identified in the literature; positivism and constructivism (also referred to as interpretivism) (Patton 2002; Robson 2002; Silverman 2005). Positivism is underpinned by the assumption that an objective world exists and as such searches for facts, truths and causes of social phenomena independent from the subjective states (Gray 2004; Guba and Lincoln 2004). The purpose of research therefore is to discover objective truth, and inquiry should be based on data collected through ‘scientific methods’ that can be observed, measured and studied as objects (Topping 2006) and not philosophical speculation (Gephart 1999; Gray 2004). Philosophically, quantitative research fits neatly within this tradition. Positivism enjoyed prominence as the dominant epistemological paradigm from the 1930s through to the 1960s (Guba 1990; Gray 2004). During the 1970s and 1980s however, concerns were raised about the limitations of quantitative data and methods associated with positivism. The ‘death’ of positivism became a recurrent theme in qualitative research texts (Robson 2002; Gray



2004; Silverman 2005) as constructivism was increasingly acknowledged as a viable alternative to positivism.

Constructivism provides an alternative to the traditions and foundations of positivism for conducting disciplined inquiry. For the constructivist researcher reality is not a rigid thing. Truth and meaning do not exist in some external world but are created by the individuals involved in the research; meaning is constructed not discovered (Hughes 1994; Denzin and Lincoln 1998; Gray 2004). Reality does not exist within a vacuum; its composition is influenced by its context (Hughes 1994; Trochim 2006). As such many constructions of reality are possible because 'just as human beings are different, so are the societies and cultures in which they live their lives' (Topping 2006 p158). Philosophically, qualitative research fits neatly within this tradition.

None of the two epistemological positions presented above is the best; each is an alternative that, according to Guba (1990), deserves to be considered on its merits. For this project that required a degree of collaboration between the individuals who had directly experienced the phenomenon under consideration (malignant melanoma) and the researcher, a constructivist epistemology was adopted. The potential of constructivism as a viable research paradigm for the study of human interaction has been well articulated by Guba and Lincoln (1998). These authors compare this paradigm with possible alternatives like positivism (objectivism) and come to the conclusion that constructivism offers a useful way forward. A fuller debate on constructivism will now be offered.

### 4.3 CONSTRUCTIVISM

According to Robson (2002) ‘constructivism’ is just one of a number of labels currently used to denote qualitative research based on the theory that reality is socially constructed. However, it is also referred to as ‘interpretive’ (Schwandt 1998) or ‘naturalistic’ (Lincoln 1990) and is often used interchangeably with the term constructionism (Burr 1995; Crotty 1998; Patton 2002). As heirs of the relativist tradition, constructivists express grave concerns about the notion of an objective reality which can be known (Robson 2002) and argue that the task of the researcher is to understand the multiple social constructions of meaning and knowledge. Constructivists are fundamentally concerned with subjective meaning, how individuals (constructivism) or members of society (constructionism) apprehend, understand and make sense of social events and settings and then build a theory or theorise from these multiple realities. This is quite unlike positivism which is concerned with objective reality and meaning independent of people. Constructivists argue that knowledge and truth are a result of perspective (Schwandt 1998 and Gephart 1999), hence all truths are relative to some meanings, context and perspectives.

A theoretical perspective closely related to constructivism is interpretivism. Schwandt (1998) describes interpretivism as a sensitising concept that steers researchers towards a particular outlook; whose purpose is to understand the complex world of lived experience from the point of view of those who live it. Examples of interpretivism include symbolic interactionism (SI), phenomenology and hermeneutics. This project has been influenced by symbolic interactionism.

Symbolic interactionism (SI) is a distinctly American branch of sociology most closely associated with George Herbert Mead (1934) and Herbert Blumer (1969). It is a theory about human behaviour; it is an approach to the study of human conduct and human group life (Blumer 1969; Chenitz and Swanson 1986). At the heart of SI lays the notion of a creative, consciously acting self- even though the self is not static and is the product developed in a social setting through learning and socialisation (Bilton et al 2002). This approach emphasises, indeed celebrates diversity and differences in social life which gives it liberal humanistic characteristics that according to Bilton et al (2002) refuse to judge and condemn and instead seek to understand social life on its own terms, through direct contact with the field. SI is concerned with the meanings of events to people and focuses on how people define events and reality and how they act according to their beliefs.

For all the liberal humanistic sentiment that it embodies and the attractiveness and plausibility of this account of social life, SI is not without its critiques. The first and possibly most obvious is that it tends to neglect social structures and examines human interactions in a vacuum (Bilton et al 2002; Haralambos and Holborn 2004). Questions have also been raised about the adequacy of the conceptualisation of self and action, since it is argued that SI overestimates the degree of conscious monitoring of action and manipulation of situations (Rice and Ezzy 1999). Social life is presented as a very consciously played game and hence the criticism that perhaps a greater leeway should be allowed for unconscious drives and social action that is less consciously controlled (Bilton et al 2002). Criticisms have also been made about what many see as the failure of interactionists to explain the source of the 'meanings' to which they attach such

importance (Haralambos and Holborn 2004). SI's liberal tolerance of deviant diversity has also come under fire with some (Patton 2002; Hansen 2006) asserting that this perspective can easily slip into always justifying action on its own terms without concern for the wider consequences for others.

In spite of these criticisms, the real strength of the SI approach lies not so much in its theoretical foundations as in the practical qualitative research it has generated. Writers such as Hughes (1958), Becker (1963) and Goffman (1969) pioneered qualitative methods aimed at 'getting in where the action is' and 'telling it like it is'. In other words one of the greatest strengths of this perspective and the reason it was used in this project, is because the emphasis is on trying to understand the world as it is seen by the research subject- no matter who they are. It is no wonder that SI has become one of the most influential theoretical approaches in the sociology of health and illness (Haralambos and Holborn 2004; Tibbetts 2005), with studies focusing on the processes involved in people arriving at the decision to seek professional help, the interaction between the ill person and the medical professional in arriving at a definition of the illness, and the impact on the person of being labelled as ill (Fife 1994; Aronowitz 1998; Tibbetts 2005). This is clearly in line with this inquiry which among other issues explores the patterns of behaviour and the processes that people subsequently diagnosed with MM engage in when they decide whether or not they are actually unwell and what they should do as a result of their decision.

### 4.3.1 GROUNDED THEORY

Up to this point this chapter has focused on the philosophical position of this study. This was crucial because epistemology bears heavily on the research methodology used: the former involves the *philosophy* of how we come to know the world and the latter involves the *practice* (Trochim 2006). Although methodology is also concerned with how we come to know, it is much more practical in nature. It focuses on the specific ways, the methods, that are used during a research project. Using the philosophical concepts presented above as a back drop, the chapter now turns from the ‘fluidity of chaos to the solidity of the ground’ (Patton 2002 pp 125) to examine the study’s methodology; grounded theory (GT). In this chapter GT is only discussed within its philosophical context, the procedures and tools used in the study will be discussed later in the methodology chapter (see chapter 5).

GT was famously developed by two American sociologists, Barney Glaser and Anselm Strauss in 1967. Glaser received his training at Columbia University and was influenced by Paul Lazarsfeld, considered at that time to be an innovator of quantitative methods (Eaves 2001). Glaser’s intention was to codify qualitative research as Lazarsfeld had codified quantitative research (Charmaz 2006) and the logical, dispassionate and systematic characteristics of GT methods reflect his influence. In contrast, Anselm Strauss came from the University of Chicago, often referred to as the Chicago School of Sociology (Baker et al 1992) that had a long history and tradition of qualitative research methods. Interactionist and pragmatist writings (Mead 1934; Blumer 1969) influenced Strauss whilst he was undertaking a doctorate at the university (Eaves 2001; Charmaz 2006). It is widely acknowledged that GT was developed for the purpose of studying

social phenomena from the perspective of symbolic interactionism (Glaser and Strauss 1967; Anells 1996; Charmaz 2006) and this is a reflection of Strauss's influence on the method since pragmatism informed symbolic interactionism. Denzin (1997 pp 18) has called GT 'the most influential paradigm for qualitative research in the social sciences today' and it has developed in directions its authors did not anticipate and, in the case of Glaser (1992), did not much approve (Dey 2004).

According to Charmaz (2006) Glaser and Strauss entered the methodological scene at a favourable time when qualitative research in sociology was losing ground to sophisticated quantitative methodologies. Quantitative researchers of the 1960s saw qualitative research as impressionist, anecdotal, unsystematic and biased. They advocated 'scientific logic, a unitary method, objectivity and truth (which) legitimised reducing qualities of human experience to quantifiable variables' (Charmaz 2006 pp 5). GT was formulated as a result of Strauss and Glaser's disillusionment with this prevailing positivist, verificationist paradigm which insisted that studies needed to have a firm 'a priori' theoretical orientation (Seale 1999; Robson 2002). They entered the epistemological debate with practical guidelines for action (Seale 1999; Charmaz 2006) arguing that systematic qualitative analysis had its own logic and offering a systematic framework for inductive theory generation. Although Glaser and Strauss never explicitly articulated the principles embedded in the GT method, there are nevertheless several assumptions that can be summarised as follows;

- Data collection and analysis occur simultaneously

- Codes and categories are constructed from the data, not from preconceived logically deduced theoretical frameworks
- Constant comparative analysis, which involves making comparisons during each stage of the analysis
- Advancing the process of discovery and theory generation during each step of data collection and analysis rather than the verification of pre-existing theories
- Writing memos to elaborate categories, identify their properties, define the relationship between different categories and pick out any gaps
- Theoretical sampling whose aim is theory construction rather than population representation refines, elaborates and exhausts conceptual categories
- Literature review is conducted after developing an independent analysis
- Systematic application of GT analytical techniques progressively leads to more abstract analytic levels

GT is ideal for this research study because it makes its greatest contribution in areas in which little research has been done (Punch 2000; Hutchinson and Wilson 2001), hence it is suitable for examining the pre-diagnostic experiences of MM patients. Many of the variables relevant to the concepts of this phenomenon are yet to be identified and any core variables that are identified can be used in later projects to test, verify or extend the qualitative hypothesis that will emerge from this initial research (Punch 2000). In addition, GT was chosen over other methods of qualitative inquiry like phenomenology or ethnography because it is one of a limited number of methodologies with the potential to produce explanatory linkage between concepts (Dey 2004). In contrast, other qualitative

methodologies often aim for rich descriptions or inductive analysis of text to create meaning related to events or experiences. GT thus will enable the researcher to take analysis further than a mere description of the pre-diagnostic experiences of people with malignant melanoma and offer explanations for *why* events may have occurred. Furthermore, the GT methodology is a recognised, well developed, systematic and transparent method of data capture and analysis. Hopefully the results will be credible and useful to healthcare practitioners such as nurses and doctors who are involved in caring for melanoma patients as well as informing health promotion initiatives. Finally, and perhaps most importantly, the GT methodology was chosen because it is an approach that allows the research participants the freedom to tell their own stories and yet also enables the researcher to remain sensitive to emerging areas of interest.

The German philosopher Arthur Schopenhauer (1836) once declared that ‘change alone is eternal, perpetual, immortal’ and like everything else, over time methodologies change and evolve. Sadly, what started as a very successful partnership between Glaser and Strauss came to an end ‘in something akin to acrimonious divorce’ (Dey 2004 pp 80) and subsequent publications by Glaser and Strauss, writing alone, but mainly in Strauss’s case with a new co-author Corbin, revealed differences in how its originators envisioned GT and its use (Babchuk 1996). Benoliel (1996), a pioneer nurse grounded theorist, declared that GT was undergoing a decade of diversification and today, over a decade later, this statement is still valid. The methodology continues to grow, maturing and branching, being affected by multiple experiences and new ideas encountered in the world of inquiry. Dey (2004) argues that there is no such thing as ‘grounded theory’ in the sense of a single



unified methodology that is tightly defined and clearly specified. Rather, there are different interpretations of GT, the classic version (Glaser and Strauss 1967), Glaser's version (1978, 1992), Strauss's version (1987), Strauss and Corbin's version (1990; 1998), Charmaz's version (2000, 2003, 2006) and a few other less prominent versions. None of these interpretations is the 'right' one, each has its own underlying epistemology, theoretical underpinnings, procedural steps and intended product. From among these various interpretations a researcher must make a choice and, sometimes, their own adaptations to the methodology (Charmaz 2006). For this research study the GT approach described by Charmaz (2000, 2003, 2006) was chosen and utilised as a framework to focus data collection and analysis. A rationale for this choice will now be provided.

#### 4.4 CONSTRUCTIVIST GROUNDED THEORY

In their original statement of the method, Glaser and Strauss (1967) invited their readers to use GT strategies flexibly in their own way. Charmaz (2000; 2003; 2006) accepted this invitation and adds one such alternative: constructivist grounded theory. When the project was first conceived, Strauss and Corbin's (1998) interpretation of GT seemed like the 'obvious' choice. This was mainly due to the researcher's limited exposure to the variations in GT. However as the study progressed it became more apparent that although a GT methodology was appropriate, the researcher shared Eaves (2001) and Benoliel's (1996) sentiments that Strauss and Corbin's (1990, 1998) approach introduced a complicated technique that was too procedural and bureaucratic especially for a novice researcher attempting to undertake a research project for the first time. In addition to this, an in-depth study of their methods reveals that although fragments of ontological

relativism are discernable in their work, Strauss and Corbin mainly endorse a realist ontology and arguably positivist epistemology. In their efforts to maintain objectivity, for example, they advocate taking ‘appropriate measures’ to minimise the intrusion of the subjectivity of the researcher to the research (Strauss and Corbin 1998 p 43). They assume an external reality that researchers can discover and record through analytical questions, hypotheses and methodological applications thereby engaging in silent authorship (Charmaz and Mitchell 1996). This involves writing about their data as distanced experts adapting an objectivist stance. On the other hand, the constructivist approach described by Charmaz (2006) places priority on the phenomena of study and sees both data collection and analysis as created from the shared experiences of researcher and participants and a product of the researcher’s relationship with the participants. Charmaz (2006) argues that we are part of the world we study and the data we collect, as such, we construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices. This approach to GT is more in tune with a symbolic interactionist theoretical perspective in that from as close to the inside of the experience as they can get, the researcher studies how participants construct meanings and actions.

In the field of qualitative research it is generally accepted that no researcher can be totally free from bias and most will have some knowledge about the topic under study. While this is accepted in Strauss and Corbin’s (1998) text, the role of the researcher is to actively attempt to minimise this ‘bias’. This, they argue, can be done by taking proactive steps. These include keeping a journal to keep track of one’s thought process and biases, taking thorough field notes that can be analysed for bias as the research progresses and reviewing

the literature only after independent analysis of the data as doing so before might prejudice the researcher. Glaser (1992) is more ruthless in his outlook and argues for a completely emergent grounded theory, asserting that any other approach inevitably leads to forcing the data into a priori categories. As an advocate of Charmaz's interpretation of GT, my argument is that using this methodology has enabled me to freely acknowledge that my clinical experience and actions I have taken as a researcher have influenced this inquiry. The narratives emerging from the interviews conducted will inevitably be constructed through the interaction of what the participants wished to disclose and my own beliefs, values and aims. Added to this, following discussion with my supervisor, herself an experienced grounded theorist and other more experienced colleagues and through reading the work of other people who have used this methodology, I am confident that constructivist GT provides the appropriate framework for this inquiry. The aim of this research is not to produce results that can be generalised to all MM patients but rather, to provide novel insights about the pre-diagnostic experiences of MM patients based on the empirical evidence from this particular group of participants. The grounded theory used in this study produces local and specific constructed realities in the relativistic ontological sense. Unfortunately, due to the constraints of the PhD process and the decision to only study pre-diagnostic delay from the patients' perspective the opportunity to verify an emerging theory was not available. The study uses many of the tools of constructivist GT methodology but stops short of claiming a substantive theory. Instead, it presents a core psychosocial process and a limited theoretical elaboration of that process.

## 4.5 THE RIGOUR DILEMMA

### 4.5.1 ESTABLISHING RIGOUR

In constructivist grounded theory, the sentiment that society exists in a state of flux and is being constructed and reconstructed through social interaction has its birth in constructivism. Such a fluid view of the construction of reality however, does have its problems. If society is constantly under construction then this means society and individual understandings are not stable therefore meaning, and in this context meanings in data are also subject to revision. This immediately raises questions about the quality or rigour expected of a research study given the traditional emphasis on reliability and validity. If reliability pertains to the consistency of research findings (Kvale 1996), how can consistency be guaranteed in an unstable environment? And since validity means truth represented as the extent to which an account accurately represents the social phenomena to which it refers (Hammersley 1990), in a world where there is no stable basis for truth there is the possibility of two kinds of errors – type 1 error which is believing a statement to be true when it is not and type 2 error which is rejecting a statement that in fact is true (Polit and Beck 2004; Silverman 2005).

According to Silverman (2001) another potential problem with assessing data from a constructivist perspective is narrowness. For example, some interview researchers complain that following a constructivist approach means the interviewer simply focuses on the conversational skills of the participants rather than on the content of what they are saying and its relation to the world outside the interview. Many constructivists, like Holstein and Gubrium (1995; 2003) accept that there is some justification for this alleged

‘narrowness’ and declare that combining a concern with both form (how?) and content (what?) is possible. In other words, ‘understanding *how* the meaning-making process unfolds in the interview is as crucial as apprehending *what* is substantively asked and conveyed’ (Holstein and Gubrium 2003 pp68). Having said this, Silverman (2001) asserts that Holstein and Gubrium’s answers to the charge of narrowness leaves them open to the criticism of being inconsistent. He points out that ‘what’ questions are precisely the concerns of positivists and constructivists who want to use interview data to answer such questions are simply backtracking to earlier positions.

Perhaps the most heated attack against constructivism is what Schwandt (1998) describes as the problem of criteria. What, he asks ‘is an adequate warrant for a subjectively mediated account of intersubjective meaning? In the absence of some set of criteria, such accounts are subject to the charge of solipsism and relativism’ (Schwandt 1998 p. 246). Constructivism, it appears, has no values. It seems to tolerate everything (all accounts are equally good) and stands for nothing. Worse, according to Gergen (1999) it discourages commitment to any set of values or ideas, after all any account is just a construction. Since constructivists decisively reject the idea that certitude is possible and believe that knowledge and belief can be based on inferences (non-foundationalism) (Smith 1990), they appeal to non-foundational resolutions to the problem. According to Schwandt (1998) these resolutions include using procedural criteria as grounds for judging the goodness of interpretations (Guba 1990) and subtle realism (Hammersley 1990).

However, despite their efforts, Smith (1990) argues that constructivists have pushed their non-foundationalism so far that now they are tangled in a completely unacceptable relativism and to get out would mean essentially redefining themselves. This point of view is rejected by Barrett (1978) and Sandelowski (1993) who warn that in a bid to produce ‘good’ qualitative work researchers are in danger of succumbing to the ‘illusion of technique’ (Barrett 1978): of making rigour an unyielding end in itself at the expense of perfecting a craft. Sandelowski (1993 p1) goes on to point out that there is an inflexibility and an uncompromising harshness and rigidity implied in the term rigour that ‘threatens to take researchers too far from the artfulness, versatility, and sensitivity to meaning and context that mark qualitative works of distinction. It is as if, in a quasi-militaristic zeal to neutralise bias and to defend research endeavour against threats to validity, there is a preoccupation with building fortifications against attack than with creating the evocative, true-to-life, and meaningful portraits, stories, and landscapes of human experience that constitute the best test of rigour in qualitative work’. She goes on to argue that in qualitative research, rigour is ‘less about adherence to the letter of rules and procedures than it is about fidelity to the spirit of qualitative work (pp 2).

From the arguments presented above, it becomes clear that the issue of ‘quality’ in qualitative research, in this case constructivist GT, is part of a much larger and contested debate about the nature of knowledge that is generated by qualitative research, whether its quality can be legitimately judged and, if so, how (Mays and Pope 2000; Patton 2002; Hansen 2006). This is part of a wider epistemological debate, which falls outside the scope of the thesis. Nonetheless good research practice demands that researchers be as

transparent about their methods as possible (Hansen 2006) and as such the next few paragraphs will outline the approach to rigour in this study.

#### 4.5.2 RIGOUR - A BALANCING ACT

A brief look at history reveals that during the 1980s concepts of reliability and validity were commonly used to assess the rigour of qualitative research (LeCompte and Goetz 1982; Brink 1987). Several researchers during this period began to question and challenge the appropriateness and adequacy of measures of reliability and validity for the assessment of rigour in qualitative studies (Guba and Lincoln 1981; LeCompte and Goetz 1982; Sandelowski 1986). Lincoln and Guba (1986) proposed that constructivist inquiry demanded different criteria from those inherited from the ‘conventional’ (positivist) paradigm. They developed four ‘parallel criteria’ suggesting;

- Credibility as an analogue to internal validity
- Transferability as an analogue to external validity
- Dependability as an analogue to reliability
- Confirmability as an analogue to objectivity

Above all this, they viewed these criteria as addressing ‘trustworthiness’ itself an analogue to the term rigour. They emphasised that constructivist inquiry should be judged by dependability (a systematic process systematically followed) and authenticity (‘reflexive consciousness about one’s own perspective, appreciation for the perspective of others, and fairness in depicting constructions in the values that undergird them’ Patton 2002 p 546). These alternative criteria have since been endorsed and utilised by other researchers (Sandelowski 1986; Yonge and Stewin 1988; Hamberg et al 1994) and are now frequently presented in qualitative research textbooks. Commenting on these criteria, Hansen (2006)

declares that they are useful for qualitative researchers at two different levels. First, at a conceptual level because they encourage new ways of thinking about rigour and quality in qualitative research and second because they provide terms to describe qualitative rigour when writing about or discussing research. However, they too have become imbued with authority and researchers feel that they must justify their work against these criteria.

Patton (2002) advises that the first step to take in order to enhance the quality and credibility of the research findings is for the researcher to acknowledge their subjectivity and personal biases. Denzin (1989) refers to a number of scholars who have concluded, as he does, that every researcher brings preconceptions and interpretations to the problem being studied regardless of methods being used. From an objectivist perspective, neutrality and impartiality, though difficult to achieve, are required of the researcher. In contrast, constructivist analysts are expected to deal with these issues through conscious, committed reflexivity and analyse how their perspectives interact with the perspectives they encounter (Patton 2002). Patton (2002) remarks that reflexivity reminds the qualitative researcher to be attentive to, and conscious of, the political, social, cultural, linguistic and ideological origins of their own perspective and voice as well as the perspectives and voices of those they interview and of those to whom they report. Although a reflexive account will be presented at the end of this thesis, the findings chapters (chapter 6 to 8) will also include reflections from the researcher. In addition, to enhance the quality and credibility of the research, a detailed account relating to analytical procedures used in the study will be presented in the next chapter.



Recognising the limitations of constructivism as a research paradigm is probably the next logical step towards enhancing the quality of research. A critical glance at constructivism reveals that as a method of inquiry it has its shortcomings. This is because it is a human construction (Guba and Lincoln 2004) and as such is subject to human error. 'No construction is or can be incontrovertibly right; advocates of any particular construction must rely on persuasiveness and utility rather than proof in arguing their position' (Lincoln and Guba 1998 p 201). The researcher aligns herself with the constructivist perspective and as such, the challenge was to collect and now present, in a balanced way, meaningful data in spite of the potential problems inherent in constructivism. When presenting the research findings the researcher acknowledges that they are not solid facts or irrefutable evidence about why people make the choices they do and sometimes delay in presenting their MM symptoms for diagnosis and treatment, but need to be considered in relation to the context in which they were grounded. It can only be assumed that the findings are valid in a particular context and therefore cannot be automatically generalised to all melanoma patients. In line with the constructivist tradition, the researcher is more interested in understanding MM presentation delay within a particular context than in hypothesing about generalisation and causes across time and space (Patton 2002).

Constructivism is viewed by its critics as disillusioning because it reveals the artificial basis of truth (Gergen 1999). If reality is constructed as people go along, how can a researcher take what the participants in a study said seriously? To the constructivist the answer to this question lies not in the realms of 'truth' but in the spheres of interaction and relationship (Gergen 1999; Guba and Lincoln 1998). Indeed they are suspicious of causal

explanations and empirical generalisations applied to complex human interactions and cultural systems (Patton 2002). Instead, they offer perspective and encourage dialogue among perspectives rather than aiming at singular truth and linear prediction. From this viewpoint, the aim of this research study was not to obtain 'truth' but rather to gain a deeper understanding of the human dimensions of malignant melanoma and why people make the choices they do; to capture and represent multiple perspectives rather than to seek a singular truth. In this sense, the opinion that society is being constructed and reconstructed through social interaction and as such there is no stable universal truth but multiple realities is a strength, not a problem and data is assessed not for its 'truth' but in terms of its descriptive richness that helped the researcher and the research participants to construct a mutual reality.

## **5. CHAPTER FIVE**

### **THE RESEARCH DESIGN**

#### **5.1 INTRODUCTION**

After outlining the theory and thinking behind the research design in the last chapter the logical next step is to give an account of the practical components of the research project. This chapter attempts to do that. It provides an overview of the research design from the beginning of the project to its completion. In the main, the chapter deals with the handling of data during the project; how it was accessed, collected and analysed. It begins by giving a descriptive account of how the participants in the study were identified, accessed, approached and interviewed. This is followed by a detailed account of how constructivist grounded theory techniques were practically used to analyse the interview data. Ethical issues arising from the research are considered next and finally various challenges experienced during the research project are discussed.

##### **5.1.1 THE RESEARCH SITE**

The first practical issue to consider was where the study would be located where the phenomenon of interest (presentation delay in MM) occurred in significant numbers. A local teaching hospital in West Yorkshire was chosen. This was a fairly straightforward decision to make because the hospital was my former place of work and from my experience working there I knew that a significant number of patients presented for treatment with extensive invasion of disease. In addition, on a practical level the hospital's location and catchment area were readily accessible. Having said this, because I was

returning to my former place of work, there is a school of thought that to avoid a conflict of interest clinicians should not research their own patients (Britten 1995). This is mainly because the patients might feel under pressure to give answers they perceive would please the researcher. This was a concern in this study but after some discussion with my supervisor, the dermatology consultant and the skin cancer clinical nurse specialist (CNS) it was decided that it was unlikely that I would encounter a large number of my former patients because my major duties lay in the treatment of other skin conditions and not in the diagnosis of MM. If I did encounter former patients, rather than perceive it as problematic I decided to adopt Hoddinott and Pill's (1997) stance that since rapport and trust had already been established, such interviews had the potential to be very successful. Added to this, as a novice researcher, working in a familiar environment with individuals who were not only interested in the research but also willing to help was advantageous. It was decided that the Consultant Dermatologist would act in the role of a second supervisor for the researcher and the skin cancer CNS was also willing to help facilitate the study. Following these initial meetings and agreements, a formal application was submitted to the local research ethics committee (LREC) for ethical approval to undertake the study.

### 5.1.2 INCLUSION AND EXCLUSION CRITERIA

The principal inclusion criteria in this study were men and women above the age of 18 who had received a positive diagnosis of a thick melanoma ( $>0.76\text{mm}$ ) in the last eighteen months in order to minimise recall bias. Recall bias occurs when the way a respondent answers a question is affected not just by the correct answer, but also by their memory and it has been suggested that the longer the time lapse since an event occurred, the more

likely the recall bias (Coughlin 1990). Potential participants had to be able to speak English. Whilst an understanding of cultural differences is very important, participants who were unable to read, write or speak English were not included in this study. This is because first, MM rarely presents in darker skinned populations (Cancer Research UK 2005; also see section 1.4.3 in chapter one) and secondly the resource implications of funding interpreters was beyond the parameters of this work and this is recognised as a limitation. That said, once access to the site was negotiated it became clear that no non-English speaking potential participants were in the available population

### 5.1.3 ETHICAL APPROVAL

In the UK, Local Research Ethics Committees (LRECs) are charged with the ethical review of National Health Service (NHS) research using human subjects and NHS premises and facilities (Department of Health 2001; National Research Ethics Service 2007). The dual role of LRECs is to protect research subjects and patients, and to facilitate research which results in new and better treatments and health service delivery (Alberti 2000). Since their emergence in 1967, partly in response to the Declaration of Helsinki (World Medical Association 2000) and the recommendations of the Royal College of Physicians (1967), LRECs have evolved slowly and have had a battery of criticisms levelled at them (Gilbert et al 1989; Dolan 1999; Samanta and Samanta 2005). Several studies have described the difficulties associated with obtaining ethical approval and systems to review ethical aspects of health research, especially qualitative research, have been criticised and found wanting by nurses (Lorentzen 1998; Dolan 1999; Tod et al 2002). One of the major criticisms has been that since the majority of LREC members tend to be from a scientific or medical background, they are often not familiar with

qualitative methodologies and are therefore unable to judge whether the proposed research is appropriate or not (Samanta and Samanta 2005).

A further more recent criticism is the bureaucracy associated with ethical and research governance approval (Jones and Bamford 2004; Galbraith et al 2006; Emery-Barker et al 2008; Hackshaw et al 2008). As experienced during filling out the appropriate paper work to submit this project for ethical approval, this criticism is valid. The process was protracted and characterised by excessively complicated administrative procedures such as filling out lengthy application forms for both ethical and research governance approval, producing additional documents such as the researcher and her supervisors' curriculum vitae, insurance documents, information leaflets, patient letters and the research proposal. This made the process of obtaining ethical and governance approval a challenge, even before the actual project had begun.

Unlike the studies described in the literature, once the forms were submitted, obtaining ethical approval from the LREC most closely associated with the teaching hospital foundation trust where this study took place was a relatively uncomplicated and straightforward process. To begin with, the LREC was composed of members from a multitude of disciplines and walks of life including nursing, university lecturers, social work, lay people and doctors. This meant the committee members could provide experience and expertise in the assessment of qualitative studies. The major issue that aroused some contention, especially from the two lay members of the committee, was the exclusion of people who could not speak English from the study. Their major concern was

that this could be perceived as an indirect way of excluding individuals from certain ethnic minority groups from the study. It was explained to the committee that although the importance of inclusion was noted, as MM rarely presents in darker skinned populations, this was unlikely to be a concern. Added to this since the research was being conducted as part of a PhD qualification there were insufficient resources to translate patient information sheets and consent forms and engage the services of a translator. This seemed to satisfy the committee and subject to a few minor amendments like adding the university logo and a version number on the patient information leaflet, the research was granted the committee's approval.

Despite obtaining ethical approval for the study, data collection could not commence due to delayed governance approval from the research and development department of the Trust. Having obtained approval from the LREC, the researcher assumed that getting permission from the research and development department of the Trust to continue with the study would be straightforward. Unfortunately this process was fraught with difficulties and frustrations. A sizable amount has been written about the difficulties of getting ethical approval for research projects (Gilbert et al 1989; Dolan 1999; Halligan and Donaldson 2001; Samanta and Samanta 2005) but this is not so when it comes to information about research and development offices. After numerous phone calls, visits to the Trust research and development offices and finally an audience with the research and development director of the Trust, permission that should have reportedly taken about three weeks to get was finally granted after three months. Despite the researcher's questions, no one at the research and development office could clarify what the concerns

were and it can only be assumed that the application was lost under the mountain of paperwork the office is responsible for. Approval to commence the study was granted in mid December 2005 and the approaching Christmas holidays meant it was inappropriate to start data collection. Data collection began in January 2006 bringing the total period of delay to just under four months.

#### 5.1.4 RECRUITMENT STRATEGY

##### (i) Identifying

After receiving the necessary permission to commence the study, potential participants who fulfilled the inclusion criteria were identified from electronic databases kept by the Dermatology Out-patients Department (OPD) and the Skin Cancer CNS's records. Since the researcher had no access to Trust records identifying potential patients for inclusion in the study was undertaken by the Skin Cancer CNS and the Consultant Dermatologist. This was beneficial because it eliminated the chance of the researcher contacting individuals who did not know they had cancer or who were otherwise inappropriate for the study. All patients presenting with a thick melanoma ( $> 0.76\text{mm}$ ) at diagnosis were automatically eligible to be entered in the study. As it turned out, all the patients recruited reported a delay of more than three months before seeking medical attention for their symptoms, thereby putting this study in line with other studies that have used time intervals rather than depth of lesion as indicators of presentation delay.

##### (ii) Approaching

In the original research proposal (see appendix 2) the plan was that the consultant dermatologist would send a letter (see appendix 3) to all potential participants who met the eligibility criteria introducing the study and inviting them to participate. This letter



emphasised that willingness to participate in the study would have no implications on the treatment they were receiving or would receive in the future. Enclosed in the same envelope were an addressed prepaid reply envelope, an objection slip for those who did not wish to be involved and an information sheet that was written in clear unambiguous language, comprehensively describing the study and providing a range of contact details if further information was required (see appendix 4). The participants then had a period of two weeks to refuse to participate in the study. After receiving all the refusals, the Consultant then passed the contact details of all those who were willing to participate to the researcher. Initially, 25 letters were sent out to potential recruits and 17 people were recruited in this way.

28 other individuals who agreed to participate in the study were recruited directly by either the Consultant or the Skin Cancer CNS. Both kept patient information sheets about the study in the clinics. If the patient met the inclusion criteria they were informed about the study and given the information sheets. If they expressed an interest they were asked if they would be happy for the researcher to contact them directly after a week when they had had a chance to read through the information they had received. If they did not object, their contact details were then passed on to the researcher. As such it is not possible to give an accurate number of those who refused to participate in the study. Although this approach was a slight deviation from the protocol agreed with the LREC, the number of people recruited as a result of the Consultant and Skin Cancer CNS's involvement was possibly better than it would have been if just the letters were sent out. Furthermore it can be argued that this process of recruitment was better for the patients because those who

refused to participate and vulnerable patients were ‘protected’ from the researcher and those who expressed an interest had a chance to immediately ask the clinicians (experts) questions before deciding whether they wanted their contact details passed on to the researcher.

### (iii) Recruiting

Two weeks after receiving the letters and a week after seeing either the Consultant or the CNS, the potential participants received a phone call from the researcher. The researcher introduced herself and asked them if they had had a chance to read through the information sheet and whether they were willing to participate in the study. Of the 25 letters that were sent out, six people sent back objection slips to the Consultant and a further two refused to participate in the study when the researcher called them. 29 individuals agreed for the researcher to contact them directly after seeing the Consultant or the CNS but one was ill when the researcher called and decided not to participate. A total of 45 individuals agreed to participate in the study. Arrangements were then made to interview them at a location and time that was convenient to them. A description of the participants is provided in Table 5.1. Pseudonyms are used to protect identity.

Table 5.1 Details of Research Participants

NO:	NAME	AGE RANGE	SEX	MARITAL STATUS	OCCUPATION	TUMOUR LOCATION	BRESLOW THICKNESS
1	Sue	65-74	F	Widow	Retired Housewife	Back	1.4mm
2	Paul	35-44	M	Married	Outdoor worker	Head	2.4mm
3	Simon*	45-54	M	Married	Professional	Foot	2.0mm
4	Luke*	75+	M	Widower	Retired Armed Forces	Shoulder	2.3mm
5	June	55-64	F	Married	Full-time Carer	Leg	1.9mm
6	Matthew*	65-74	M	Married	Self employed	Back	1.0mm
7	Tom	75+	M	Widower	Retired outdoor worker	Back	10.2mm
8	Samantha	25-34	F	Single	Office worker	Thigh	2.6mm
9	Jane	55-64	F	Widow	Health worker	Leg	6.2mm
10	Peter	55-64	M	Married	Full-time Carer	Back	9.6mm
11	Paula	75+	F	Widow	Retired Public Service	Leg	2.9mm
12	Eddy	65-74	M	Married	Managerial	Shoulder	3.2mm
13	Winnie	75+	F	Widow	Retired Housewife	Arm	3.0mm
14	Pat	65-74	F	Married	Lower managerial	Arm	1.7mm
15	Joan	55-64	F	Married	Professional	Leg	2.5mm
16	Martin	45-54	M	Divorced	Skilled worker	Trunk	7.8mm
17	John*	35-44	M	Single	Skilled worker	Head	2.7mm
18	Lisa	35-44	F	Married	Office worker	Arm	4.5mm
19	Bob	55-64	M	Married	Managerial	Arm	11.5mm
20	Nancy	25-34	F	Married	Professional	Arm	2.3mm
21	George	55- 64	M	Married	Semi-skilled worker	Shoulder	2.5mm
22	Len*	55-64	M	Married	Managerial	Trunk	1.9mm
23	Kiki	55-64	F	Divorced	Retired performing artist	Leg	3.1mm
24	Frank	35-44	M	Married	Self employed	Arm	2.6mm
25	Agnes	75+	F	Widow	Retired Unskilled	Head	4.8mm
26	Steve*	65-74	M	Widower	Managerial	Back	2.5mm
27	Andrew	45-54	M	Cohabiting	Self employed	Leg	1.7mm
28	Clive	65-74	M	Married	Public Service	Shoulder	3.7mm
29	Donna	25-34	F	Single	Health worker	Leg	1.76mm
30	Dave *	65-74	M	Married	Retired Armed Forces	Back	9.9mm
31	Mary	45-54	F	Single	Disabled	Head	2.3mm
32	Ken	65-74	M	Married	Retired self employed	Back	1.8mm
33	Ian	45-54	M	Divorced	Unemployed	Back	2.7mm
34	Charles	65-74	M	Widower	Retired Professional	Head	1.8mm
35	Julie	45-54	F	Cohabiting	Professional	Leg	5.4mm
36	Kate	45-54	F	Married	Office worker	Back	2.0mm
37	Hugh*	45-54	M	Married	Professional	Back	2.7mm
38	Barry	35-44	M	Divorced	Semi-skilled worker	Arm	3.3mm
39	Carol	55-64	F	Married	Public Service	Leg	2.1mm
40	Amy	35-44	F	Single	Health worker	Leg	0.6mm
41	Lulu*	55- 64	F	Married	Self employed	Head	0.2mm
42	Andy	45-54	M	Married	Professional	Trunk	0.5mm
43	Bev	55-64	F	Married	Self employed	Arm	0.65mm
44	Colin	15-24	M	Single	Student	Back	0.4mm
45	Chris	65-74	M	Married	Professional	Trunk	0.5mm

\* Participants who had spent time living in sunnier climates

Interestingly the individuals who took part in the study are representative of the population who are likely to get MM discussed in the literature (see chapter one). First, since cancer (and MM) is mainly a disease of the elderly, over 50 per cent of the sample were over the age of 60. Having said this, when compared with other cancers melanoma incidence is high in younger adults (see section 1.4.1) (Cancer Research UK 2006). Around a third of all cases occur in people aged less than 50 years and it is the second most common cancer in the 20-39 age group, again reflected in the research sample. Second, about 50% of the sample either came from fairly affluent backgrounds as reflected by their lifestyles and occupations and were therefore more likely to have enjoyed foreign holidays or had been exposed to higher amounts of UV radiation by their occupations; an obvious example being Paul (interview 2) who, at the time of the interview had been an out door worker for 16 years. Other less obvious examples include all the military personnel who had spent time in countries such as Saudi Arabia or Africa with sunnier climates than Britain and other individuals who had been expatriates in various counties around the world. These individuals will be discussed further in the findings of the study. Finally, an analysis of the profile of each participant (see appendix 1 for example of first 10 interviews) reveals that most of them are ‘true MM candidates’ (see section 1.3.2 in chapter one) with fair skin, blue or green eyes and red or blond hair. By analysing the characteristics of this sample it is interesting to observe how the biology and the reality merge.

There were several priorities regarding recruitment in this study. To begin with, the potential participant needed to have a clear understanding of the study. Added to this the

researcher had to be sure that they understood that participating in the study would not in any way affect the treatment they were receiving or would receive in the future and that whatever they disclosed in the context of the research interview would be confidential. There are questions around confidentiality in qualitative research and some (Baez 2002; Giordano et al 2007) have argued that it can not be truly guaranteed in this type of research. This will be discussed further later in this chapter (section 5.3.3). Before the actual interview commenced, the researcher discussed these issues with the participants and went over what participating in the study entailed. After this they were asked to sign a consent form confirming (see appendix 5) that they were happy to participate in the study and had a clear idea of what that entailed.

#### 5.1.5 INTERVIEWING THE PARTICIPANTS

The original study research proposal stated that ‘Interviewing will be done in batches of six to ten people at a time in order to allow the researcher time to analyse the data using constant comparison and carefully consider how any emergent themes can be explored in subsequent interviews’(see appendix 3). In reality things worked rather differently. The researcher actually had no control over when she could interview the individuals who had agreed to participate. For example, when data collection commenced, the Dermatologist sent out 15 letters to potential participants. Two people sent back objection slips to him and one person refused to participate when the researcher called her. This meant 12 people were recruited from the original batch of letters and needed to be interviewed fairly quickly. Added to this the Dermatologist and CNS were constantly recruiting patients for the study and the researcher had to get in touch with those who had agreed to be contacted a week after their consultation. As a result 17 interviews were conducted in the space of

two months and then the pace slowed down. Interviewing occurred as patients were recruited which meant that depending on how many people were diagnosed with thick melanoma, some months had more interviews than others.

The interviewing took place over a fifteen month period. Most of the interviews were conducted during the day in the interviewees' homes, which sometimes meant that the researcher had to drive great distances around the county to get to informants homes. A few of the interviews (eight) took place in a comfortable 'bereavement' room at the hospital, a further three interviews occurred at the informants' workplaces over their lunch breaks and one interview took place at the participants home in the evening after she had returned from work. According to Swanson, et al (1997) the convenience of the venue, the need for privacy and personal safety are major considerations for interviewing respondents and these conditions were met.

All the interviews were tape-recorded using a microcassette recorder and an omnidirectional microphone. No one objected to being recorded, although some appeared cautious to begin with. Unfortunately one woman insisted on sitting so far away from the microphone that the sound was too faint to be intelligible at times. Another woman occasionally covered her mouth with her hand when she spoke. It can only be assumed that this was a habit she had but it meant that some of that interview was difficult to discern. A third interview was also found to be of limited use because unknown to the researcher the microcassette developed a problem during the interview and occasionally stopped recording. In addition, one interview was aborted after five minutes because the

researcher was concerned that the interviewee appeared rather unwell. During another interview she decided to turn the tape recorder off when it became apparent that the participant had other concerns and was not focused on the research at hand. In a final incident, although the researcher finished the interview she decided to discount it because she felt the views expressed were not the participants own. These three incidents will be discussed in greater detail later in this section. In total, thirty-nine full and three partial interviews were included in the interview analysis of this study.

Central to any research investigation is the asking of questions along with the pursuit of their answers (Strauss and Corbin 1998). As a grounded theory researcher, qualitative interviewing was used to explore, not to interrogate (Charmaz 2003). The term ‘qualitative interview’ in this context refers to a semi or loosely structured form of interviewing (Mason 2002; Pole and Lampard 2002) that was relatively informal in style. Although the interviews had a structure in that a number of topics, themes and issues had been identified (see appendix 6 for interview guide), there was not a complete and sequenced script of questions. Instead the approach was designed in such a way that the interviews had a fluid and flexible structure in order to allow unexpected themes to be developed with the interviewee(s). The questions used had to be sufficiently general to cover a wide range of experiences, but also narrow enough to elicit and explore the participant’s specific experience. In fact, the only questions that were asked the same way with all participants were their Fitzpatrick skin type (see section 1.3.2 in chapter one), their hair and eye colour and demographic questions (marital status, occupation) found at the beginning of the interview guide. It was felt that starting by asking these questions would

be less threatening and ease the participants into the interview process (Charmaz 2003). In practice a few of the patients appeared to be extremely eager and began to talk even before the consent form was signed and the tape recorder switched on. In such cases, these first questions were asked further within the interview.

As the theoretical perspective guiding this research was symbolic interactionism, the participants were given an opportunity to tell their story in their own words. Interviewees were viewed as ‘experiencing subjects’ (a subject or person who experiences or has experienced a given phenomenon) who actively construct[ed] their social world, ‘meaning makers’ and not merely as passive vessels of answers or treasuries of information awaiting excavation’ (Holstein and Gubrium 1995 pp.3). The aim of the interviews was to try and obtain an insight into the individuals’ thoughts and feelings about their situation, the explanation and motives for actions that led to a MM diagnosis and their construction of the ‘meaning’ they attached to receiving that diagnosis. In this sense, the participants were actively involved in the interview process. While some participants relished this chance and needed very little prompting to talk, the opportunity ‘to tell their story in their own words’ seemed to be problematic for some participants. When invited to talk about their experiences they were reluctant, either because they could not or did not want to. In these circumstances the interviewer had to prompt them and ask more questions as per interview guide. All participants were thanked for participating in the study after their interviews and given an opportunity to ask the researcher any questions they may have had.



The interviews lasted an average of about an hour and field notes containing observations about the ambience of the interview situations and non-verbal behaviour, the ease of communication and outside interferences were added as a memo to the participants file as soon as possible after the interview. Every participant's profile containing their demographic data, Fitzpatrick skin type, hair and eye colour as well as their Breslow thickness was also included in their file. Their 'presentation journey' (modelled around the model patient delay; see appendix 1) was diagrammatically presented and included to the profile. Reflexive notes and comments summarising my perceptions about the participant, the interview context and the whole 'case' were recorded. As discussed earlier, three of the interviews were not suitable for inclusion in the data collected for this study. Tom (interview 7) initially appeared to have full mental capacity albeit a little frail. He signed the consent form and indicated that he was happy to proceed. However as the interview progressed he appeared increasingly confused and was having difficulties recalling what had happened even after being prompted. After about five minutes I decided to follow Arksey and Knights's (1999) advice to be prepared to abandon the interview if it is not working. On my way home I decided, in my duty of care as a nurse, that it would be prudent to pass through the medical centre where Tom was a patient and asked the district nurses to check on him. When I called the nurses a few days later to find out what had happened, I was informed that Tom had spent a couple of nights in the hospital suffering from dehydration but was now back home in better health. I decided not to reschedule the interview.

The second interview which was subsequently discarded from data analysis was with Paula (interview 11). She had experienced a series of very tragic circumstances at about the same time as her MM was diagnosed after a two year period of delay. She was still traumatised and talked at length about her experiences. She clearly associated these events with the MM diagnosis although there appeared to be little connection. I felt that it would be inappropriate to pursue my research objectives and pressure her to talk about the delay preceding her MM diagnosis and decided to adopt the role of the sympathetic listener. I asked her if she wanted me to switch off the tape recorder which she agreed to and apologised for 'not being very useful' to me. I sat and listened to her. I do not know whether she found talking to me a source of release or simply a new ear to hear a well rehearsed story.

In the final incident Mary (interview 31) was known to experience slight learning difficulties. An inclusive approach was adopted to avoid the temptation to exclude individuals with learning difficulties from research projects because they are often perceived as less capable of participating in the consent process than other people (Tee and Lathlean 2004). Mindful of this potential discrimination, Clifford et al (1998) urge researchers to challenge these perceptions and find ways of accommodating 'research orphans' in the research process as they often have valid contributions to make. Added to this, in order to demonstrate that the principle of justice, one of the four *prima facie* (absolute) moral principles developed by Beauchamp and Childress (2001) was upheld elements such as equality, transparency and democracy had to be evident in the recruitment process (Beauchamp and Childress 2001). After discussing the issue with the

CNS, who had initiated recruitment, I decided to approach Mary to participate. I called her and she appeared very keen to participate. However, on the day of the interview her sister was present and decided to 'join' the interview. Normally I would have had no objections but in this case the sister completely took over the interview. When I asked Mary a question, her sister would quickly answer, often overshadowing Mary. Mary seemed completely over powered and when her sister momentarily went out to answer the phone, she apologised for her sister's behaviour and explained that she often felt the need to 'protect' her. I did finish the interview but because I had heard so little from her, I could not be sure that it reflected Mary's experiences or opinions. As such I decided not to include it in the study. This means that no narrative from the interviewees I have called Tom, Paula and Mary have been included in the interview analysis, and only forty-two of the original forty-five interviews form the basis for the results presented in this thesis.

#### 5.1.6 TRANSCRIBING THE INTERVIEWS

It was my intention to transcribe the tapes as soon as possible after the interview. As a novice qualitative researcher I had limited understanding of the significant and vital role of transcription in the qualitative research process and it was not until I undertook my own transcription that I began to realise the magnitude and significance of this activity. Gray (2004) warns this process is very time consuming. Without a transcription machine, the first two interviews I transcribed took over 20 hours each and did much to build my dread of transcription. To compound the problem, my typing skills are not exceptional and I often could not hear what was said clearly the first time round and frequently needed to replay the tape. However, in spite of these problems and my misgivings about it, it was from these experiences that I learnt that transcribing is a very valuable part of the research.

Like Bird (2005) who writes a detailed account of her ‘journey into the world of transcribing’ I began to appreciate that far from just being mechanical, transcribing includes elements of analysis and interpretation. Issues such as tone of voice, volume, non verbal sounds (or silences) and non topic related comments all added to the richness of my data. None the less, I quickly realised that with no access to a transcribing machine, I would be unable to keep up recruitment levels and conduct a lot of interviews because of the amount of work involved in transcribing.

Fortunately, I was able to secure some funding from a local MM support group for transcribing and engaged the services of a very experienced transcriber who often sent transcripts back to me within a few days. This enabled me to work more efficiently and quickly as I was then able to replay all the tapes and make corrections, add annotations and comments – or as Tilley (2003 p.752) called them, the researcher’s ‘interpretive, analytical, theoretical [finger]prints’. As Tilley (2003) points out, research rigour is enhanced when qualitative researchers interrogate the ways in which hired transcribers influence the analysis and therefore trustworthiness and reliability of data as they translate tape into text. The textual data obtained from transcribing the interviews was then imported into the NVivo7 software management system, a computer package specifically designed to help researchers analyse qualitative data.

#### 5.1.7 COMPUTER ASSISTED DATA ANALYSIS

Computer assisted data analysis offers an alternative to traditional manual data analysis. Several programs including NVivo, Atlas and Ethnograph are easily available to researchers. One of the greatest advantages of using qualitative analysis software is that it

can effortlessly manage large mountains of data and help to organise and keep track of the many messy records that go into making a qualitative project (Charmaz 2000; Bazeley 2007). The programme used to assist the data analysis in this project was NVivo 7. QSR International, the developers of NVivo only promise to provide a set of tools to assist in the analysis of qualitative data (QSR International 2007) and the program does not think for the researcher. Instead it uses the computer's capacity for recording, sorting, matching and linking to assist the researcher to answer their research questions from the data without losing access to the source data or contexts from which the data have come (Kelle 2004; Bazeley 2007).

However, these programs do not escape controversy. Coffey and Atkinson (1996) express concern that these programs overemphasise coding and promote a superficial view of grounded theory. They also note that mechanical operations are no substitute for nuanced interpretive analysis. Charmaz, whose version of grounded theory this study follows, also expresses reservations about these programs arguing that these software packages appear more suited for objectivist grounded theory than constructivist approaches and may unintentionally foster an illusion that interpretative work can be reduced to a set of procedures. Such concerns, however, are not shared by Fielding and Lee (1998) who did not find substantial empirical evidence for them in their systematic field study of user's experiences with computer-assisted qualitative data analysis programs. Since the PhD is essentially a learning process I took both views on board and used the opportunity to learn how to use both manual and computer assisted methods of data analysis. I began the analysis manually and then with better experience moved on to computer assisted analysis.

An example of how computer assisted analysis was utilised in the study is presented in the next section of this chapter.

## 5.2 TECHNIQUES AND PROCEDURES OF CONSTRUCTIVIST GT

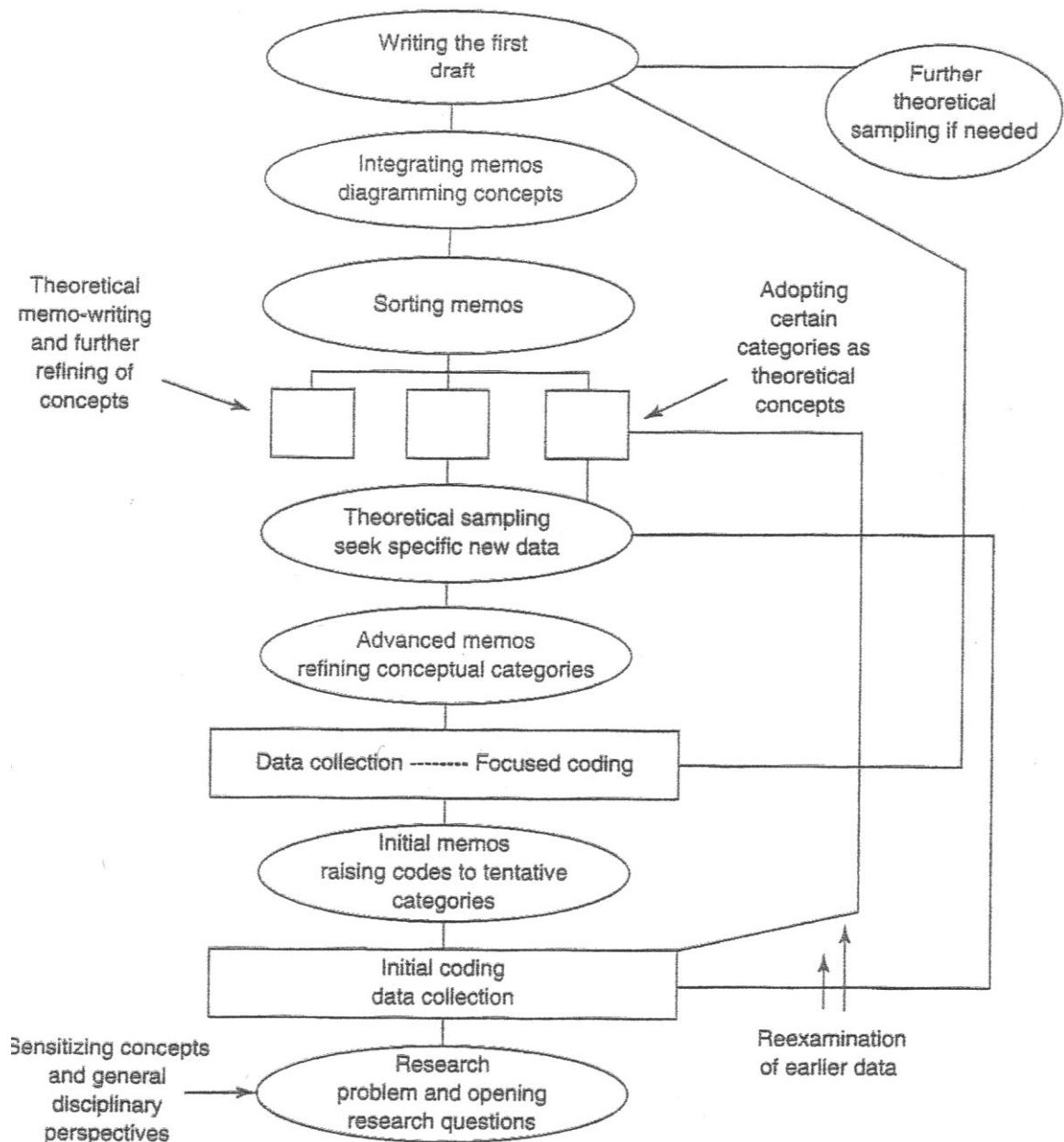
Like other interpretations of grounded theory (GT), the constructivist approach as outlined by Charmaz (2000; 2003; 2006) is based on a set of procedures used together to facilitate the development of a theory. Charmaz (2006 p.11) has recently diagrammatised the constructivist GT analysis strategy (Figure 5.1) to give an overview of the processes and procedures involved in this method. These procedures are presented here in linear form but, in line with the spirit of GT, the research process is not linear and the procedures were used flexibly throughout the study. The following pages give an outline of the techniques and procedures used and include examples of the process in action to provide clarity and transparency.

### 5.2.1 GROUNDED THEORY CODING

According to Charmaz (2006) GT coding generates the bones of analysis. Theoretical integration then assembles these bones into a working skeleton. Thus, she argues, coding is more than a beginning; it shapes an analytical frame from which the analysis is built. The aim of the analysis is to reduce/transform the vast amount of material generated in order to ‘sharpen, sort, focus, discard or organise data in such a way that ‘final’ conclusions can be drawn and verified’ (Miles and Huberman 1994 p.11). In other words, through coding the researcher *defines* what is happening in the data and begins to grapple with what it means (Charmaz 2006). The process of coding is seen as giving the

researcher a condensed, abstract view of the data which helps to try and make sense of seemingly disparate phenomenon (Glaser 1978).

Figure 5.1 The Grounded Theory Process (Source: Charmaz 2006 p.11)



Within the GT method there is a detailed system of coding and concept formation first developed by Glaser and Strauss (1967) that involves an ongoing process of constant comparison. This constant comparison involves continually comparing data with data to find similarities and differences. Comparing data within the same interview, comparing statements and incidents between different interviews and as codes develop and categories emerge making comparisons within and between these. As events are constantly compared with previous events, new relationships and topological dimensions may be discovered (Goetz and LeCompte 1981).

One of the major strengths of the GT method advocated by Charmaz (1990, 2000, 2003, 2006) is that it presents a set principles and practices, not prescriptions or packages offering the researcher flexible guidelines, not methodological rules, recipes and requirement (Charmaz 2006). Generally speaking, coding in this interpretation of GT consists of at least two main phases:

- a. Initial or open coding which involves naming each word, line or segment of data with the general goal of the discovery and generation of tentative concepts and categories from these codes (Glaser 1978; Charmaz 2003, 2006)
- b. Selective or focused coding in which the most significant and frequently appearing initial codes are used to sort, synthesise, organise and conceptualise large amounts of data (Glaser 1978; Stauss and Corbin 1998; Charmaz 2003, 2006).

In short, coding, in constructivist as well as other interpretations of GT, is about the researcher capturing what they see in the data into categories that simultaneously describe and dissect the data. In essence, it is ‘a form of shorthand that distils events and meanings



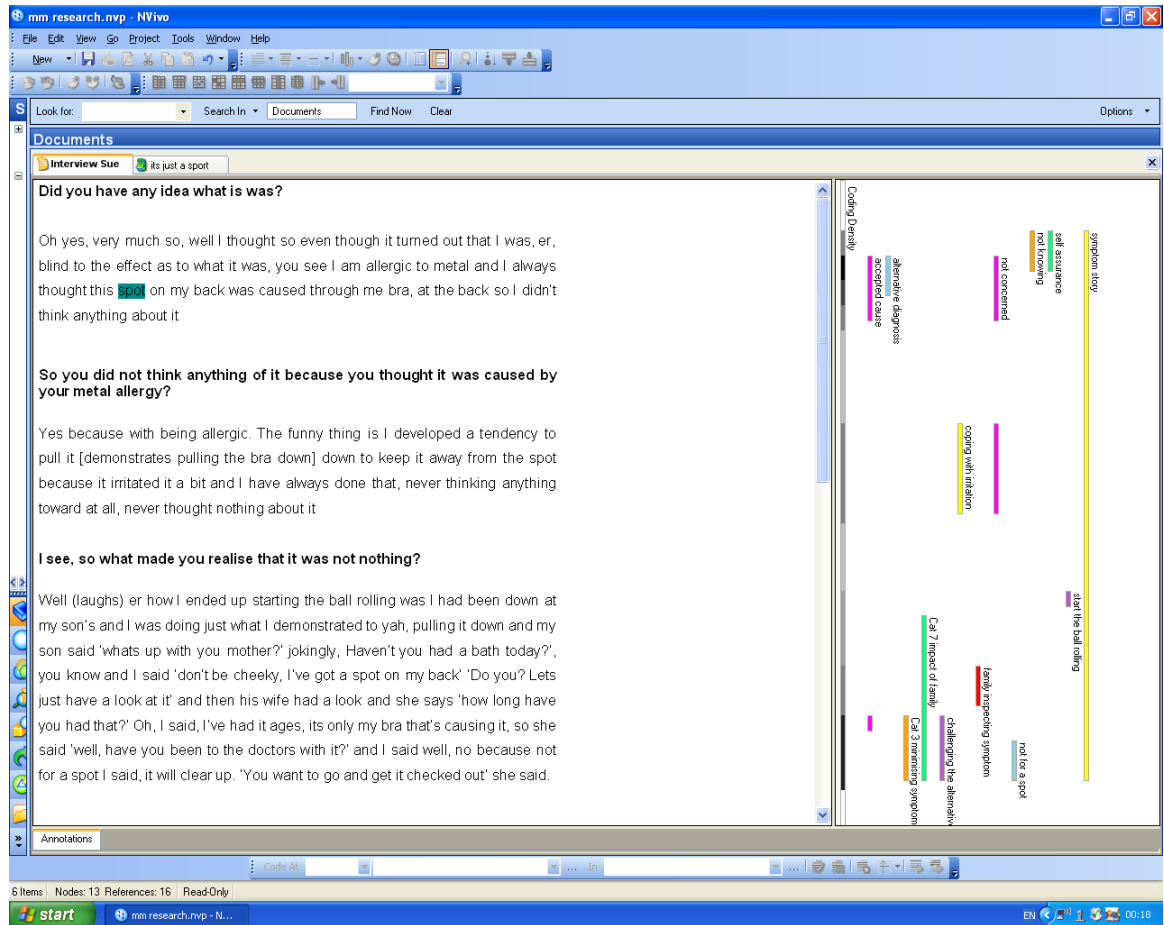
without losing their essential properties' (Charmaz 2003 p.684). An account of how the data in this study was coded will now be presented.

(i) Initial Coding

As discussed earlier, the interview transcripts and field note texts from the data collected during this study were imported into the NVivo7 qualitative data analysis software management system. Initial coding began by using line by line coding. This is a means of generating codes inductively and in practice meant each line of written data was named. Words, phrases, sentences and incidents that looked significant were identified, highlighted and given conceptual labels that reflected their significance. The initial codes were open (literal), iterative (what I thought was going on) or *in vivo* (used participants' exact words or phrases). *In vivo* codes were especially helpful in assisting me to preserve participants' meanings of their views and actions in the coding itself. Significant words, lines, phrases, sentences and incidents were placed in the system as nodes (codes) and allocated a label and an operational definition. Figure 5.2 shows an example of coding in the NVivo management system. The text on the left represents the interview data and the coding strips on the right identify coded lines of text. This example demonstrates 21 lines of text containing 10 codes. Here Sue, one of the participants in the study describes her symptom experience and how 'the ball started rolling' in terms of her going to seek help. Examples of initial codes indicated include- 'alternative diagnosis' 'self assurance' 'coping with irritation'. An example of an *in vivo* code in the text is 'starting the ball rolling'. Category coding is also indicated and includes 'impact of family' and 'minimising symptoms'. This example also shows an annotation (highlighted in dark green) where a comment or reflection was made on the word. Also opened but not visible

is a memo ‘its just a spot’ where throughout the analysis I elaborated on the processes, assumptions and actions that were subsumed under my codes (Charmaz 2000).

Figure 5.2 Coding in NVivo 7



(ii) Focused Coding

Focused coding is the second major phase in coding. According to Glaser (1978) and Charmaz (2006) these codes are more directed, selective and conceptual than word by word, line by line, incident by incident coding. After establishing what I considered to be strong directions for analysis through my initial intensive coding, focused coding whereby I adopted the most frequently reappearing initial codes in order to synthesise and explain

larger segments of data began. This was done in order to raise the codes into concepts (Charmaz 2006). Strauss and Corbin (1998 p.103) describe a concept as a 'labelled phenomenon... an abstract representation of an event, object or action/interaction that a researcher identifies as being significant in the data'. Similar events, happenings and objects are grouped together under a common classification. They call this process *conceptualising*. Concepts with shared properties were then classified into categories. Categories are also concepts but they often subsume several concepts and 'stand for phenomena' (Strauss and Corbin 1998 p.114). In this sense categories have more explanatory power than concepts. For instance, the category 'symptom interpretation' consisted of four concepts namely 'knowledge', 'perception of symptoms', 'perception of health and illness' and 'perception of risk' and answered, in part, why presentation delay in MM occurred. Focused coding is a higher level of conceptual analysis and abstraction that helps to define and develop the 'core category', the one variable central to the phenomenon under study. This overarching category, the 'lead character' in the story of the research, might be broad in focus but it should be able to integrate and explain the links between other categories that have emerged from the data and bring an explanatory element to the work by answering the question 'what is going on in the data?' (Glaser 1978; Strauss and Corbin 1998). According to Glaser (1978) the core category or process has six essential characteristics

- It recurs frequently
- It links the various data together
- It explains much variation in the data because it is central
- It has implications for a more general or formal theory

- It permits maximum variation in analysis
- As it emerges from the data, the theory is able to move forward

In this study the core process was chosen after re-reading the interview memos, drawing a number of diagrams of the interconnections between the two major categories identified and thinking about what was going on in the data, the central processes that were occurring. A number of relationships were proposed, tested and refined. When I felt that the core process identified in this study (discussed in chapter 9) largely met Glaser's (1978) characteristics, focused coding was considered complete.

### 5.2.2 MEMO WRITING

Qualitative researchers typically keep a journal to document how they have moved from the initial forays in their project to arrive at their conclusions; hence some refer to the journal entries as an audit trail for the project. Looking at figure 5.1 these journal entries (commonly referred to as memos) play a crucial role throughout the entire grounded theory process because they link coding to the writing of the first draft of the analysis; a crucial intermediate step that moves the analysis forward (Charmaz 2006). Glaser (1978) refers to them as the *bedrock* of theory generation and to Charmaz (2006) they form the *core* of grounded theory because they elaborate processes defined in focused coding. Hence memo writing prompts grounded theorists to raise their codes to conceptual categories. In *Handling Qualitative Data* Lyn Richards (2005), one of the authors of NVivo, compares the memo writing process to keeping a ship's log with its careful account of a journey and provides detailed suggestions about what might be recorded there. Without such a record, she argues, it would be difficult to keep track of when and how insights were gained and ideas developed. It would also be difficult to pull together

the evidence needed to support the research conclusions. Without memos, too, precious, fleeting ideas are likely to become forgotten ‘as the data marches on, the next task is upon you, or the complexity of it all begins to overwhelm’ (Bazeley 2007 p. 29)

In accordance with Charmaz (2006) two main types of memos were used during this study. First early memos were recorded concerning what I thought was happening in the data. They often took the form of annotations or short reflective summaries of what I thought was going on within the interview accounts which helped me to ‘add flesh’ to initial codes and direct and focus further data collection. Second, advanced memos ‘fractured’ the data by taking the codes apart analytically. Constant comparison formed the backbone of these memos and explicit comparisons, data with data, concept with concept, category with category, were made across the data. The properties of categories were defined as well as the conditions under which they developed, were maintained or changed and their relationships with other categories. The final type of memos written during this project I refer to as personal memos because unlike the ship’s log, these were often private documents which recorded my frustrations and joys as I worked through the project. All memos were written and stored in NVivo. The excerpt below is an example of a memo written after some of the early interviews where the role of ‘risk’ in seeking help for MM symptoms is questioned.

Who is at risk of getting a MM? Certainly the people who have had MM do not seem to think of themselves as 'being at risk'. There is wide spread knowledge that the sun is a risk factor for skin cancer but somehow that does not seem enough to jolt them into action. What makes someone perceive themselves to be at risk? What is risk? What do I mean by risk? What do they mean by risk? Are our definitions of the word the same? What are its characteristics? What conditions are necessary for someone to perceive themselves as being 'at risk'? Participants seem to view risk in terms of a POTENTIAL adversity, something that might happen rather than a REAL threat. The fact that the word 'risk' has so many different meanings might cause communication problems but I think I need to investigate it further. If professionals work hard at publicising the risk factors for MM would it be enough to make people stop and realise that they are at risk?

This memo led me to pursue some of the questions raised in subsequent interviews as well as re-examine transcripts from earlier interviews. More importantly it directed me to review the literature around the impact of risk perception in help seeking behaviour and enabled me to crystallise my thoughts around this concept that turned out to be an important category.

### 5.2.3 THEORETICAL SAMPLING AND SATURATION

Theoretical sampling is defined as the process of data collection whereby the researcher simultaneously collects, codes and analyses the data in order to decide what data to collect next. Deciding where to sample next according to the emerging codes and categories is theoretical sampling (Glaser 1978; Coyne 1997; Charmaz 2006). It is difficult to discuss theoretical sampling without referring to the GT method, as theoretical sampling is a central tenet of the method. The term 'theoretical' relates to the selection of what or who to study based on developing analysis, ideas or theory. Issues of importance and people are sampled on the basis that they are perceived as 'experts' in whatever phenomenon is under study. Unfortunately there are many variations of 'theoretical sampling' described in the literature and the terms 'purposeful' and 'theoretical' sampling are often viewed synonymously and used interchangeably which I found rather confusing when trying to

understand the true essence of theoretical sampling. To make matters worse researchers who claim to have used the GT method often do not describe their sampling strategy in sufficient detail which makes it harder to replicate the technique.

In spite of these limitations, this study attempted to follow the advice available in order to satisfy the demands of the GT method. Glaser (1978) acknowledges that in the initial stages of a study, researchers will 'go to the groups which they believe will maximise the possibilities of obtaining data and leads for more data on their question. They will also begin by talking to the most knowledgeable people to get a line on relevancies and leads to track down more data and where and how to locate oneself for a rich supply of data' (p. 45). Thus theoretical sampling does have a 'purposeful' element. In fact, in his more recent work Glaser (1992), whose explanation of theoretical sampling is somewhat embraced by Charmaz (1990; 2006), stated that 'in short, theoretical sampling in grounded theory is the process by which data collection is continually guided' (p. 102). Therefore, according to Coyne (1997) more accurate terms for theoretical sampling could be 'analysis driven purposeful sampling' or 'analysis governed purposeful sampling'. The general procedure of theoretical sampling adopted during this study was to elicit codes from the raw data from the start of data collection through constant comparative analysis as the data came in. These codes were then used to direct further data collection, often through modifying the interview questions, from which the codes were further developed theoretically with properties and theoretically coded connections with other categories until each category was saturated and gathering fresh data no longer sparked new theoretical insights or revealed new properties for the core categories (Charmaz 2006).

Theoretical saturation was seen to have been reached when the core sample of thirty-six ‘delayers’ was complemented by a ‘theoretical’ sample of six individuals with superficial tumours (<0.76mm thick) who described presenting early for diagnosis. This was done in order to examine in greater detail the issues that had been raised by the study. For instance, it was important to establish whether the social aspects of delay identified during the study only applied to individuals who delayed. As such the decision was taken to investigate this aspect further by interviewing individuals who had not delayed in order to determine whether the same issues affected them and, if so, how they had handled them compared to the delayers. It was during this phase that continued analysis no longer yielded any new insights or concepts and as such it was felt that the time to stop collecting data had come.

### 5.3 ETHICAL ISSUES ARISING FROM THE RESEARCH

The purpose of this section is to highlight some of the ethical challenges that arose during this research project. Many a volume has been written about ethics in nursing practice and research, and although there appears to be no definitive set of ethical principles to govern the profession there are a number of guidelines available. These include the NMC Code of Professional Conduct (Nursing and Midwifery Council 2004) which offers some general fundamental ethical principles on nursing practice, the Research Ethics Guidance for Nurses produced by the Royal College Of Nursing (2007) as well as the Government’s guidelines for research in the National Health Service (National Research Ethics Service



2007) - all available on the internet. This account presents an overview of the major ethical issues encountered during this research project and how they were managed.

### 5.3.1 INFORMED CONSENT

Autonomy, the view that respect for individuals self-determination or self-governance is of supreme moral importance (Thompson et al 2000) is a central principle associated with health and social science research ethics. According to Beauchamp and Childress (2001) the basic tenet of this principle is consent. They define informed consent as an individuals' autonomous authorisation to participate in an intervention or research. Gillon (1985 p 13) extends this definition by adding that informed consent is a 'voluntary, uncoerced decision made by a sufficiently competent or autonomous person on the basis of adequate information and deliberation, to accept rather than reject some proposed course of action that will affect him or her'. The recruitment strategy described earlier (see section 5.1.4) illustrates that issues of consent were taken very seriously during this study. Indeed, in the current research climate the ethical concern is not one related to denying anyone their right to informed consent as this would be difficult to justify (Behi 1995) and not permitted by any ethical committee (Tierney 1995). The real ethical challenge is in knowing whether the researcher can claim that the participants had been adequately informed and consent genuinely given and achieved – especially when it relates to a qualitative study. This is because in qualitative studies like this one, it was difficult to obtain a meaningful consent at the outset because the researcher did not know in advance how the study or interviews would evolve. For example, because of the methodology used, grounded theory, the nature and scope of the study extended as a result of the initial

data collection and analysis. As such, although at the onset a considerable effort had been made to anticipate the exact nature of the data to be collected and what exactly the risks, benefits and time commitments the participants would have to make were, there was no certainty. This inevitably involved a degree of speculation.

In situations such as these, Polit and Hungler (1999) suggest that consent should be an ongoing, transactional process. This view is supported by Munhall (2001) who states that informed consent, although vital, is a static past tense concept unlike qualitative research which is an ongoing, dynamic changing process full of unpredictable events and unforeseeable circumstances. This being the case, they (Polit and Hungler 1999 and Munhall 2001) argue that a past tense consent is not adequate and that process consent is more appropriate for a qualitative study. So even though the participants in the study had already given their 'informed consent' at the beginning of the project, they can not be expected to anticipate their feelings about participation (Oliver 2003) or tell in advance if they will find the experience enjoyable or stressful. Indeed some parts of the research process that probed personal feelings and actions, such as asking people to justify their decisions and explain why they had chosen to do what they did, especially those individuals who delayed in presenting their symptoms to the General Practitioner for example, had the potential to be at least disconcerting and possibly distressing.

Inherent in the principle of autonomy is the freedom of the participants to withdraw from the research at any time (Polit, Beck and Hungler 2001; Oliver 2003) without giving notice or explanation. During the study, in an attempt to act in an ethical manner, the

researcher facilitated the negotiation and renegotiation of the consent process by stressing to participants that even though they had started the interview they could end it at any time. The question ‘are you happy to continue?’ was asked frequently. All the participants in the study responded positively and apart from the two incidents described above, no other interviews ended prematurely.

While it seems obvious to state that all the participants were treated with courtesy and respect there are people who could have been easily manipulated and needed to be protected from abuse. For instance, the researcher’s background as a dermatology nurse might have made it difficult for some to refuse to participate in the research project, especially if she had met and cared for them in the past. Although she no longer had any ‘power’ over the treatment any of the participants received, because she was a nurse some may have still viewed her as the voice of authority (Munhall 2001) thereby making it difficult for them to send her away. Others might have felt obliged to take part in the research out of a sense of altruism (Seymour and Skilbeck 2002), as a gift, a way of saying thank you for the care they had been given, albeit not necessarily directly to the researcher but more likely to the skin cancer CNS and Consultant Dermatologist. In such situations it would have been easy to take advantage of their vulnerability. As nurse researchers, Johnson and Plant (1996) recounted experiencing similar challenges during a research project and they dealt with the situation by disclosing their professional identity only when appropriate or necessary. They also claim that they had to make a deliberate effort to make it easy for people to refuse to take part in their study. In a similar manner, in this project deliberate steps were taken to ensure that no former patients encountered in a nursing

capacity (there were two of them that participated in the study) - or any other participant-felt pressured to participate in the study. These 'deliberate steps' included reminding potential participants that the researcher was no longer employed by the Trust and emphasising that refusing to participate in the study would not affect their care in any way.

### 5.3.2 DOING NO HARM

In spite of all the good intentions and efforts made to act in the participants' best interests some invasion, as it were, occurred to the people involved. Munhall (2001) warns that there is a danger of researchers cajoling themselves if they refuse to acknowledge that no matter how laudable their aims there may still be a degree of inconvenience and discomfort in participating in qualitative research. During the study although none of the participants came to any physical harm, Mc Haffie (2000) points out that there was a possibility that emotional, psychological and social harms may still have occurred. For instance, in an interview situation the interviewer may have wished to discuss a topic that the interviewee appeared reluctant or uneasy about. In such cases, the manner in which the interviewer chose to respond was clearly an ethical issue. They could have either continued with the process of data collection or chosen to withdraw- ethically speaking both decisions can be justified.

On one hand the principle of non-maleficence, another one of the four *prima facie* moral principles developed by Beauchamp and Childress (2001), demands that no harm befall the participants (Beauchamp and Childress 2001) and therefore the interviewer must withdraw. The principle of beneficence on the other hand, recognises that although some

discomfort may occur to the individual, the 'greater good' (Gillon 1994) of gathering data will benefit more people and therefore the interview must continue. This is why ethical issues can at best be described as thorny. In such circumstances which principle should have been upheld over the other? Fortunately during this study only two tensions of this nature arose. In common with other nurses before me, I decided in advance that should a conflict of this nature develop, I would enact the deontological principle that human beings are to be treated as ends and not means (Munhall 2001) and therefore, the therapeutic imperative, to borrow Munhall's (2001) words, of nursing (advocacy) would take precedence over the research imperative (advancing knowledge). This is exactly what happened when I decided to exclude Paula's account from the study as described above (section 5.1.5). Although I was interested in discussing the two year period of delay preceding the MM diagnosis, I felt it was rather inappropriate to pursue my research objectives and instead allowed Paula to talk about her experiences as catharsis.

Having said this, if all issues that could be remotely sensitive to someone were avoided, then the researcher would run the risk of making the research so bland it would not have generated any useful data (Sieber 1993; Oliver 2003). What was needed therefore was to strike a balance and make compromises. This was achieved by making it clear to the participants that they could decline to answer or elaborate on a particular topic (Oliver 2003). This empowered the participants and safeguarded them from any subject areas they may not have wished to discuss. When conducting their research Johnson and Plant (1996) found giving their interviewees advance warnings of the questions they were going to ask very useful as the interviewees had time to think about their answers and this, they

believe, helped them to relax during the interview and be less apprehensive. The researcher adopted this technique and sometimes gave examples of the type of questions that would be asked when she spoke to the participants on the phone before the interviews, giving them a chance to reflect on whether they wished to answer the questions or not thereby minimising the chances of the researcher 'doing them harm'. As it turned out, most research participants answered all the questions asked and did not seem to suffer as a result of it.

### 5.3.3 CONFIDENTIALITY

Confidentiality is usually depicted as the cornerstone of research ethics (Polit, et al 2001; Oliver 2003). In most cases, the researcher has an obligation to keep the identities of the people they work with secret and according to Thompson et al (2000), maintaining the privacy of the research study participants is the main way that social scientists do no harm (non-maleficence). It is the right of all the study participants to expect that any information collected during the course of the study will be kept in the strictest confidence (Munhall 2001; Oliver 2003). Anonymity, when even the researcher cannot link the participant with the information they have provided, is often portrayed as the 'gold standard' in the literature. However, the qualitative interviewing used to collect data during the study made keeping the participants anonymous impossible (Robson 2002) therefore appropriate confidentiality procedures were implemented instead. Identifying data (name, address and telephone numbers) were removed from transcripts of the interviews and replaced by identity numbers and pseudonyms. The tapes, all personal information and any information obtained from medical records were kept locked at all

times when not in use by the researcher. Due to the growing problem of computer hacking, no personal details were kept on the computer.

Another ethical issue to consider is the use of medical records as a source of data. Even though the patients had given their permission for the researcher to have access to their medical records, there are clearly issues here with regard to confidentiality. Much as the researcher only required specific information in relation to the patient's diagnosis of MM, she inevitably became privy to other often extremely sensitive information regarding the patient's health and sometimes even personal details about their lives. As such great care was employed when handling such information and in accordance with the RCN Research Ethics Guidelines (2007) participants were made fully aware of this and reassured that any data pertaining to them was safe. Post research, confidentiality continues to be an issue that seriously needs to be considered, especially when seeking to publish the research. Regardless of the fact that pseudonyms were used, care needs to be taken to ensure that the no individual's identity will be specifically identified by the information given about their circumstances or their verbatim quotes.

#### 5.4 ISSUES ARISING FROM THE RESEARCH INTERVIEWS

At first glance, the advantages of qualitative interviewing for conducting a grounded theory study seem unassailable. While it is true that qualitative interviewing fits grounded theory methods particularly well (Warren 2002; Rapley 2004), the reality is that interviewing is not an easy option. It is fraught with hidden dangers and can fail miserably unless there is good planning, proper preparation and a sensitivity to the complex nature of

interaction during the interview itself (Denscombe 2003). Clearly, interviewing for research purposes is a challenging task and a few of the challenges experienced during this research project will now be discussed.

#### 5.4.1 INTERVIEWER EFFECTS

Research on interviewing has demonstrated fairly conclusively that people respond differently depending on how they perceive the person asking the questions (Denscombe 2003). As all the interviews were arranged through the NHS Trust, I had no say in the initial recruitment phase of the study. However, since all qualitative researchers need to consider how they are perceived by their respondents (Britten 1995), I too had to make this consideration. The patient information sheet identified me as a PhD student from the university and did not mention my nursing background. As a result some of the interviewees did not know this. Although this did not seem to bother most people, it brought about a distinct reaction in others. These individuals seemed to think I was ‘very clever’ and therefore tried not to ‘bore’ me with the mundane details of their lives or were keen to talk about my academic prowess. Examples were Sue, a housewife, who used phrases like ‘Oh but you really would not be interested in the foolish speculations of an old woman like me’ and had to be constantly reassured that I was interested in all the details of her experience and that all the information she told me would be very useful, and Bev, a successful business woman, who often said things like ‘but of course, since you are doing a PhD you probably know all this already’

For most people however, it was my nursing background that had the greater effect. As part of the introduction to the study, the CNS and Consultant who recruited most of my



participants told the potential recruits that I was nurse undertaking research so all the individuals recruited in this manner knew that I had a nursing background. In addition some people who had received letters in the post often asked me about my background and were told that I was a nurse. The general knowledge of my dermatology nursing background had two effects. First, despite the clear message on the information sheet that I was from the University, most of the recruits assumed that I worked at the NHS Trust or at least had very close links with it, and in a bid to please me, were very complimentary of the care they received. Only one lady complained about the nurses in a certain department not washing their hands and urged me to 'take this forward'.

Second, as Britten (1995) warns health professionals undertaking research, some participants may use the research opportunity as a consultation. I was asked questions about general health problems, recurrence rates, medication and one man even asked me to help him fill in his insurance claim form. Several people asked me to look at and comment on new lesions or moles they had. I did not find their desire for information a problem within the context of the interviews. The questions usually came at the end of the interview when I invited them to contribute anything else we had not covered within the interview that they felt was important. I dealt with these issues on an individualised basis. Some of the questions were simple and could easily be answered. For others, like assessing new lesions, I had to ascertain whether or not the interviewee had approached either their GP or consultant with the query. If not, I offered to refer any queries or requests for information to either the skin cancer CNS or the Dermatology Consultant, if the interviewee consented to this action being taken.

Other interviewer effects that needed to be considered were my sex, age, class, ethnic origins and accent (in this case lack of local accent), as these all had a bearing on the amount of information people were willing to divulge and their honesty about what they revealed. It is impossible to state with any degree of certainty how these impacted on the interviews. For instance, it is possible that some of the women would have been less happy to have been interviewed alone in their homes by a man, or perhaps some of the older men were not too comfortable being interviewed by a young woman who clearly was not from Yorkshire and although I do not feel I actually experienced it personally, judging by some of the comments found in the literature (Davis and Silver 2003; Descombe 2003) some participants might have been uncomfortable being interviewed by a black researcher.

#### 5.4.2 FAMILY MEMBERS JOINING INTERVIEWS

Since convenience of the venue is an important consideration, I often travelled to respondents' homes to conduct the interviews. While this often suited the respondent, it meant interviewing with their everyday lives as a back-drop. Generally, individuals tried to ensure a comfortable interview environment (often in the lounge or dining room) but occasionally minor disruptions like the phone ringing or family members arriving home could not be avoided. Although most spouses and family members tactfully kept away, two of the women and four of the men had their respective spouses present during the interview. Other people to take part in the interviews were one woman's neighbour and other one's sister. Interestingly both husbands asked if they were welcome to join the interview and I left the decision to their wives who both consented because they had

originally invited them to take part. One wife was invited to join the interview by her husband because “she had a better memory than he did” and she hesitated until I indicated that she would be welcome. The other five women (wives, neighbour and sister) just ‘joined’ in. I personally had no problem with family and friends being part of the interview and most, I felt, made a valuable contribution to the interviews, elaborating on points and adding their perspective thereby enriching the research data.

Having said this, there is an argument that other people should not be present during face-to-face interviews as they might ‘influence’ the respondent to answer in a certain way leading to distorted or evasive answers (Reuband 1992; Hartmann 1995). For instance, early family research conducted by Scheuch (1973) showed that interview answers concerning marital happiness differed depending on the location of the spouse vis-à-vis the respondent within the room: the lesser the distance, the more marital happiness was proclaimed suggesting that the respondent was possibly trying to avoid conflict and sanctions by giving replies that suited the partner. Even worse is when the third party interferes and ends up controlling or taking over the interview. These arguments on the negative impact of third persons in the interview situation are valid because as discussed above, I had to discount one interview because the participant’s sister overshadowed the participant and I did not feel the interview reflected the participant’s views. At the time I felt that if I was a more experienced researcher I might have been able to handle the situation differently. In that one incident I would have welcomed privacy and the chance to interview the participant alone. On the whole, the spouses and friend who participated in the interviews were asked to stay by the respondent and conducted themselves well,

making contributions when necessary and generally, I felt, offering support to the respondent.

I sincerely hope that taking part in this research project was a positive experience for the participants; creating feelings of being valued by others, self confidence, well being (Winterbottom and Harcourt 2004) and perhaps understanding themselves a little better. This chapter was an attempt to present an overview on the practical elements of the study and to discuss the issues and challenges that were encountered. Conducting this research project was akin to a muddy swamp with no clear cut paths and specific instructions to follow (Punch 1998) and often involved tracing a path through native territory. As a newcomer to real world research, it was inevitable that in actually *doing* the research various issues and challenges would arise. However, as Punch (1998) observes, fortunately there are experienced and wise supervisors and mentors available and professional publications and guidelines on good research practice.

PART THREE

**RESEARCH FINDINGS**

## 6. CHAPTER SIX

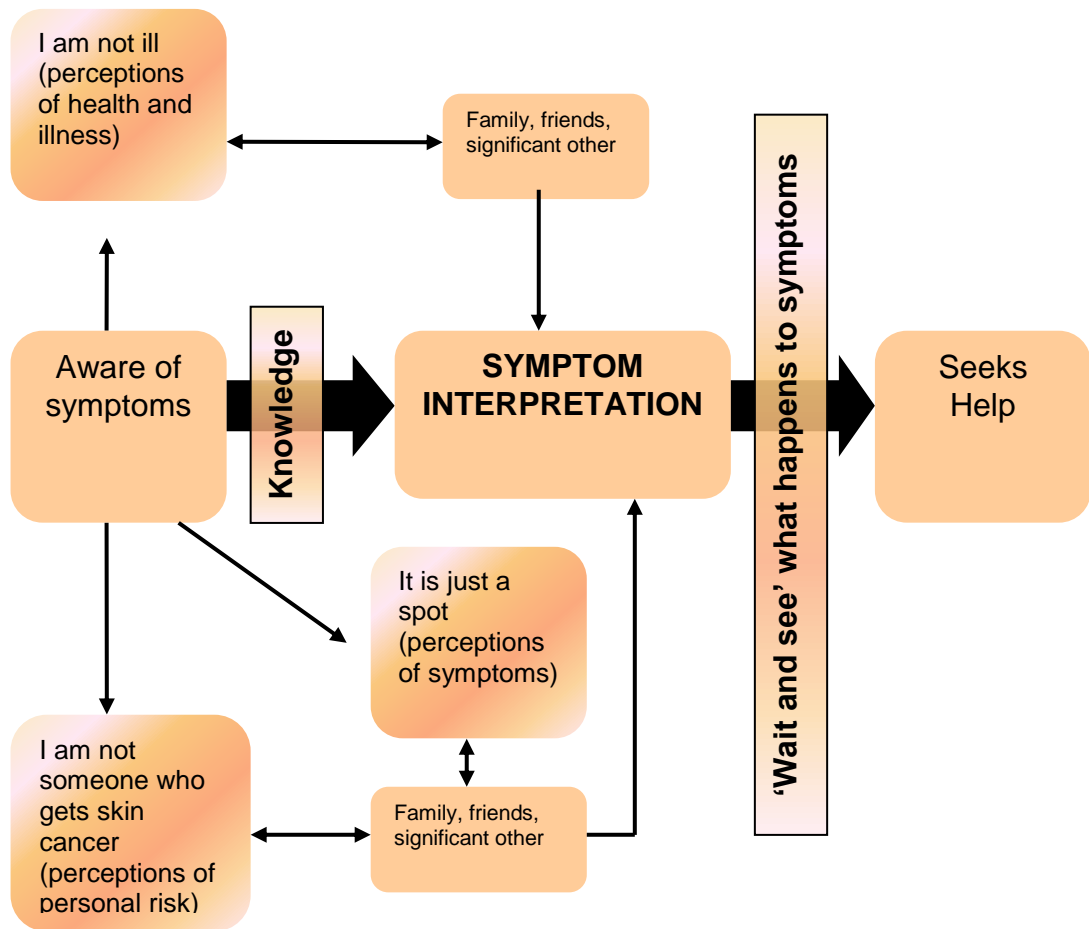
### SYMPTOM INTERPRETATION

#### 6.1 INTRODUCTION

There are many reasons why people may seek medical help, but by far the most common reason is the experience of a symptom (Petrie and Weinman 2003). Although the association between symptoms and gaining entry into health care may appear straightforward, evidence reveals that this is not the case. This is probably because many symptoms are common, non-specific and the majority are transient and benign. Hannay's (1978) study investigating symptom prevalence in the community in which individuals were asked to keep a symptom diary revealed the presence of daily symptoms. It would appear that most symptoms, while they may make the individual think about their nature and cause, do not give rise to any further behaviour such as taking medication or seeking medical help. For instance, one study (Verbrugge 1985) where people kept health diaries found that while symptoms were recorded on 38% of the days in the study period, medical care was sought for only 5% of those symptoms. This suggests that seeking medical help for symptoms is a relatively uncommon response to a common phenomenon. Dodd et al (2001 p.669) define a symptom as 'a subjective experience reflecting changes in the biopsychosocial functioning, sensations or cognition of an individual' and it is probably this very 'subjectiveness' of the symptom experience that inevitably contributes to inaction.

Having said this, whilst the majority of symptoms are transient and benign some can be a warning, an indication of something more sinister, and are therefore important cues that bring problems to the attention of the individual and clinicians (Dodd et al 2001). In an ideal situation, individuals would be able to correctly identify and interpret their symptoms and crucially, have the ability to discriminate between the benign and more sinister to enable them to act appropriately (Nyawata and Topping 2006). This chapter, the first of three findings chapters, tells the story of the research participants' symptom experiences. As discussed at length in the third chapter of this thesis the decision to go to the doctor depends, among other things, on how symptoms are perceived interpreted and evaluated (illness behaviour). As such symptom interpretation, or as in this case, symptom *misinterpretation* is identified as one of the major causes of presentation delay. If people misinterpret their symptoms then it follows that they may not take the 'right' course of action. Due to the nature of the symptoms described in this study, when individuals misinterpreted their symptoms they typically minimised them giving raise to a false sense of security, complacency and delayed presentation for medical help.

Figure 6.1 Symptom Interpretation Diagram



As illustrated by the symptom interpretation diagram created from the findings of the study presented in Figure 6.1, how MM symptoms come to be misinterpreted is a complicated process influenced by a variety of factors. In an ideal world, after individuals became aware of their symptoms they would take the fastest route to seeking help, signified by the bigger black arrows. Unfortunately the reality is often quite different. As the diagram shows, awareness of symptoms is frequently followed by diversions from the straightforward path (illustrated by the smaller black arrows) and obstacles (illustrated by the translucent text boxes) leading to symptom misinterpretation and ultimately



presentation delay. According to the findings from this study these ‘diversions’ and ‘obstacle’ namely:

- knowledge
- perceptions of risk
- perceptions of symptoms
- perception of health and illness

are responsible for the misinterpretation of MM symptoms and consequently are the major focus of this chapter. A second obstacle ‘waiting to see what happens’ adds to the delay already introduced by the misinterpretation of the symptoms and will also be discussed. Though included in the diagram and mentioned briefly at certain intervals in the chapter, the input of family, friends and significant others will be discussed more fully in Chapter Seven.

## 6.2 FAILURE TO TRASLATE KNOWLEDGE INTO ACTION

De Nooijer et al (2001b) assert that knowledge is a necessary prerequisite for anyone to be able to interpret a symptom as a signal of cancer, or judge it as serious and requiring medical attention. Previous studies examining presentation delay in MM have cited a lack of knowledge about the serious consequences of a new or growing cutaneous pigmented lesion as a major reason for patient delay (Rampen et al 1988; Blum et al 1999, Oliveria et al 1999; Schmid-Wendtner et al 2002) and this study was no exception. However what is markedly different about the results of this study compared to its predecessors is that many of the participants appeared to have a degree of knowledge about MM. Only two participants, Winnie (the oldest participant in the study) and Agnes claimed to have no

knowledge of skin cancer let alone MM before their diagnosis. All the other participants had some prior knowledge of skin cancer and MM. Most were able to identify the classical symptoms of MM such as a change in colour, increase in size, and elevation of a pigmented lesion as possible signs of MM and most knew about the association between the sun and MM. Despite having this knowledge they still delayed in presenting for medical help. It would appear that knowledge alone was not sufficient to initiate self referral, and delay seemed to be a result of a failure to translate that general knowledge into action. Participants frequently failed to make the connection between what they knew about MM and their symptoms. Eddie's story illustrates this well.

Before his MM diagnosis, Eddie, a successful 68 year old manager had a very active social life and played golf as often as he could. During the course of the interview he revealed that a couple of the friends he played golf with had both been diagnosed with skin cancer the previous year.

Eddy Yes, so I suppose I did know a thing or two about skin cancer, about malignant melanoma but, okay it sounds foolish to say it now, hindsight and all, but I guess I never really made the ....erm....connection. Even after X [his friend diagnosed with MM] I still did not look at my shoulder and think 'now wait a minute'

With the benefit of hindsight Eddy became aware of the fact that he knew more about MM than he realised and should have made the connection between his friends' experiences and his own symptoms. Stories such as Eddy's illustrate that knowledge alone does not necessitate action. Individuals have to go beyond just 'knowing' and start 'acting' if the tendency to delay presenting for medical intervention is to be reduced. Although the sample of six 'non delayers' in this study is very small, it is interesting to note that out of this sample four individuals (three women and one man) describe making the connection

between the knowledge they had about MM and their symptoms. Although one woman, Amy a 36 year old health worker, was well informed about MM, the remainder of this sub sample did not seem to possess any greater knowledge than the rest of the study participants. Nevertheless they appeared to make the connection and use that knowledge to make an informed decision and seek medical attention.

Failure to translate knowledge into action is a theme discussed in other cancer related literature. For example in their oft cited study of men with testicular cancer, Gascoigne et al (1999) found that knowledge, in the form of correctly attributing cancer symptoms did not necessarily guarantee early help seeking. In common with other studies that have investigated presentation delay in other cancers such as breast and testicular cancer (Colbert 1994; Burgess et al 2001; Mason and Strauss 2004), they found that this failure to translate knowledge into action was often attributed to fear. Fear, not only of the prospect of being diagnosed with cancer, but also of the possible treatment or misconceptions about the side effects of surgery, chemotherapy, and radiotherapy (Colbert 1994). Unlike these other studies, fear was not reported as a factor for failing to translate knowledge into action by the participants in this study. No one described fear (explicitly or implicitly) of diagnosis or treatment as holding them back from seeking medical attention. Rather, it would seem that participants' unconsciously discounted the possibility of a MM diagnosis primarily because they did not make the connection between their symptoms and their general knowledge of MM.

In some cases individuals reported delayed help seeking not because they lacked knowledge but rather because the knowledge they had was insufficient or inaccurate. Horowitz et al (2004) describes this as knowledge with gaps in depth and breadth. For example Carol a 57 year old woman narrates this problem after a question about previous MM knowledge was asked.

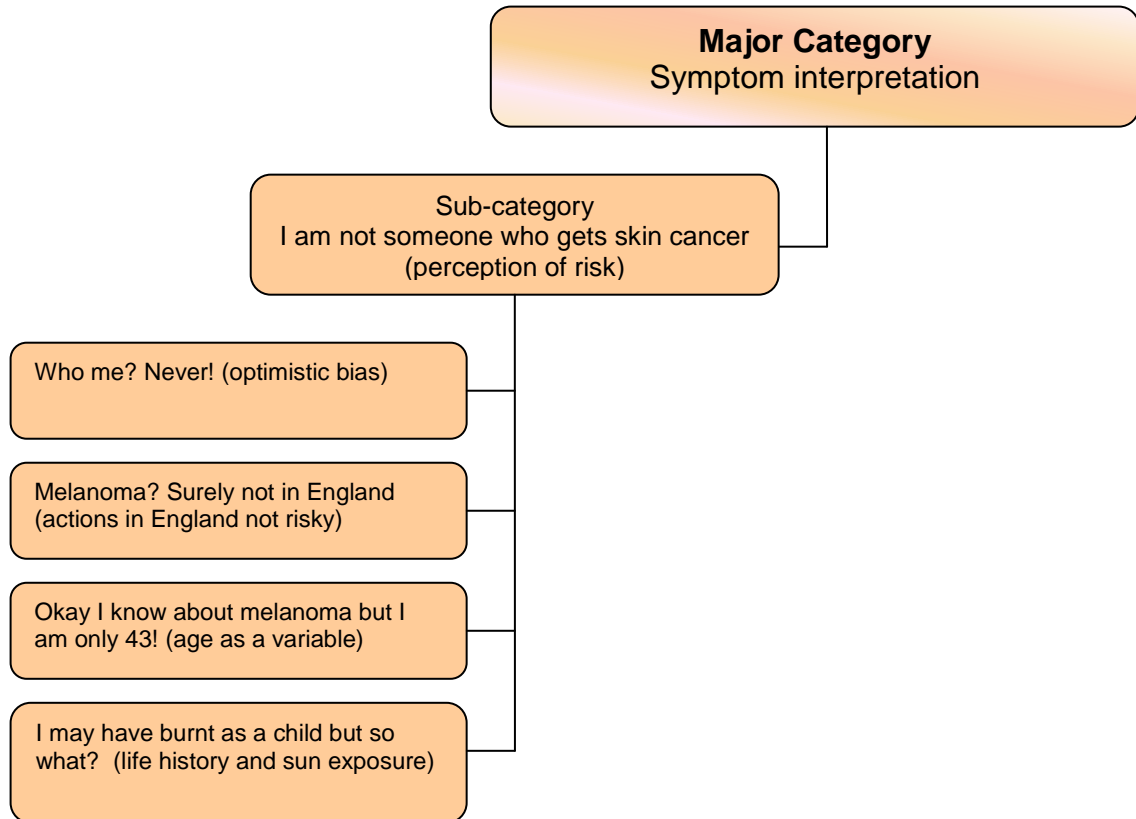
Idah So before you actually received the diagnosis did you know anything about melanoma, did you know anything about it?

Carol I thought I did and er other people I spoke to, I know somebody else whose been through not a skin cancer but who knew about it, but in reality I didn't have sufficient information or the correct information I had got a leaflet up in my bedside draw with pictures of malignant melanomas which were sort of raised nobly things, crusty things, things that bleed and I thought I did, I didn't in reality

Before she was diagnosed, Carol thought she knew enough about MM in order to make an informed decision about it and was therefore surprised by her failure to recognise the symptoms and seek for medical intervention. Carol was not alone and a number of other participants reported that it was only after they were diagnosed that they realised that they did not know as much as they thought they did. This insufficiency or inaccuracy of knowledge was often evidenced by the erroneous beliefs that many participants held or claimed to have held before their diagnosis such as cancer cannot be present in the absence of pain, a loss of energy and strength or a large bleeding tumour. Because their symptoms did not match what they thought they knew about cancer and more specifically MM they delayed in seeking for medical assistance.

### 6.3 'I AM NOT SOMEONE WHO GETS SKIN CANCER'

Figure 6.2 Perception of Risk



Having examined the role played by knowledge in the misinterpretation of symptoms the chapter will now move on to discuss how symptom interpretation was also influenced by how the study participants' perceived their personal risk of getting a MM. Perception of risk is believed to play a prominent role in the help-seeking decisions people make because it lies at the heart of the judgement about the best course of action (Slovic 1987; Slovic and Weber 2002). However, before expounding on the role played by risk perception in the decision to seek medical intervention for MM symptoms, it is instructive to define the concept of risk. There are multiple conceptions of risk. In fact as Slovic (1987), one of the leading experts on this concept points out, a paragraph written by an

expert may use the word several times, each time with a different meaning not acknowledged by the writer. Over the years the meaning of risk has changed and its use has become far more common and applied to a plethora of situations. Graubard (1990) summarises this change as follows 'It is perfectly obvious that the concept 'risk' has taken on wholly new dimensions in recent decades and is today being reflected on in ways that would have been almost inconceivable even a few years ago. The older idea, that risk is essentially a wager, which individuals take in the hope of gaining something significant, substantial, has almost disappeared from common parlance. Risk today is conceived principally as danger'. As Douglas (1992 p 40) phrases it 'risk has become a decorative flourish on the word 'danger'. When discussing the concept of risk this thesis will borrow from the definitions presented above. The term will be used to denote a phenomenon that has the potential to deliver substantial harm, a danger, a threat, a potential hazard.

Although the term 'risk' was not specifically used, the research participants volunteered their feelings of a lack of concern or vulnerability which implied that they did not perceive their symptoms as being a threat or danger to them. An examination of the sample of participant profiles provided in Appendix 1 reveals that with fair skin, blue or green eyes and blond or auburn hair most of the participants in the study could justifiably have been described as typical MM candidates. However, when asked to describe someone they would perceive as being at risk of getting MM only a hand full related their description to themselves. The open ended nature of the interviews also meant the participants were given ample opportunities to describe their own lives and experiences. Even though most of them described events that could certainly be perceived as high MM risk activities such

as living and working in sunnier climates, regularly burning as children, hobbies like gardening and walking and working outdoors they still did not perceive themselves as being at an increased risk of MM and therefore did not respond appropriately to their symptoms ultimately leading to presentation delay. Some of the reasons for their low risk perceptions will now be explored.

### 6.3.1 WHO ME? NEVER!

Research on risk perception in healthy adults shows that although this group is often reported as being 'normal' they frequently exhibit a bias known as 'optimistic bias' in which individuals typically estimate their own risk as being less than their peers regardless of the hazard (Weinstein 1982; Slovic 1987; Flynn et al 1994; Rutter 1998). While there are clearly benefits to being optimistic such as maintaining a relatively high level of self-esteem and being able to go through life without being overcome by fear (Kos and Clarke 2001), it has also been shown that unrealistic optimism can be detrimental. This is because individuals assert that they are less likely than others to experience illness, injury and other negative events and therefore these beliefs may interfere with their taking precautions in order to reduce their risk (Weinstein 1982; 1987; Clarke et al 1997). In spite of their physical and social condition, to most of the research participants skin cancer was simply something that happened to other people and not them. One of the saddest aspects of doing this research was that two respondents Peter and Bob died of their MM before the research was complete. By all accounts at 56 Bob was too young to die. His MM had developed from a mole on his arm he had had for over 20 years. Unfortunately it was a nodular melanoma (see section 1.1.2) which is the most aggressive type of MM and tends to grow more rapidly in depth and thickness than other types of MM. Naively, Bob had

done nothing about his symptoms for nearly two years, despite the fact that his mole had changed from a light brown colour to black and developed a nodule, because it never occurred to him that he might have a MM.

Idah            So you wouldn't have perceived yourself as someone who would get malignant melanoma?

Bob            No, I wouldn't, well you don't think, you always think that it's the other people and not you. So I mean that's how I put all aspects of life that its something that you are aware of but you don't necessarily change your life style until you've proved you've got it with any kind of illness if I had angina or if I had something wrong with my lungs if I had diabetes I would have to alter my diet but I haven't so I don't do anything about it until I get it.

After repeated failed attempts by his wife and daughter to get him to go and see a doctor because he was sure it was 'nothing', Bob finally entered formal health care when he needed vaccinations to go abroad and the practice nurse noticed his arm and made an appointment with the doctor for him. Unfortunately by the time he entered specialist care the MM had metastasised and could no longer be treated. He died from his MM shortly after this interview.

Numerous authors have reported a positive correlation between personal optimism, endangering behaviour and neglect of precaution (Weinstein 1982; Clarke et al 1997; Weinstein et al 2005). For example, Weinstein et al (2005) found that compared to non-smokers, smokers typically underestimated their personal risk of experiencing tobacco related illness. They also believed that they were at a lower risk of developing lung cancer than other smokers leading them to be complacent about their actual risk. In a separate study examining general and personal beliefs about sun tanning and sun protection by



assessing various perceptions of risk of skin cancer, Clarke et al (1997) found that most of the 100 participants aged between 18- 30 years they interviewed did not perceive themselves as being susceptible to skin cancer. Even when the risk of getting skin cancer from sun tanning was acknowledged, participants considered that others would get it before they personally would. The results from this study revealed that similar perceptions of invulnerability among the respondents often led them to ignore legitimate risks in their environment and made them fail to take measures to offset these risks. As Kos and Clarke (2001) observe, if people believe that negative events are less likely to happen to them it is likely that they will pay less attention to risk related information and will thus be less likely to engage in self protective behaviours.

In some cases, lower perception of risk was related to misperceptions about MM prevention. Many of the individuals in this study felt they were not personally susceptible to MM because they had 'protected' themselves. They remained out of the sun and/or protected themselves with clothing or sunscreen.

Kiki Well I use sunscreen religiously so I can not imagine that this [MM] could be a problem

Sue I have never really *liked* the sun much, so I did not really think I had anything to worry about

Steve's wife He was growing a bit bald, I always made him wear a hat you see, and I naively thought that was enough

Such expressions of invulnerability to MM were most common amongst those who thought they 'protected' themselves, with eleven participants claiming that they never thought MM 'would ever happen to me' using these words exactly. Most of the reasons given for this sentiment were sun-related but a few were related to other factors, some of

which were correct, for example ‘MM not in the family’ and others which were incorrect such as ‘I am never ill’. More of these sentiments will be discussed as the chapter progresses.

Only six respondents spoke of perceiving an increased personal risk of developing MM even though their personal risk estimation was not always accurate. One told of how his mother had developed MM at the age of 62, two cited past sun bathing behaviour as their reason for increased personal risk, another expressed fears that previous cancer (not MM) might return in another form, and the final two felt at an increased risk of MM because of physical characteristics they possessed (very fair skin and numerous moles on their bodies). Despite their increased perception of risk these people were in the sample of ‘delayers’ indicating that perception of risk alone may not be enough to make individuals seek medical attention.

### 6.3.2 MELANOMA? SURELY NOT IN ENGLAND

Another reason for low risk perception of MM susceptibility in the study was the belief that sun exposure in England is not as risky as that in other hotter countries such as Spain. It was interesting to observe how many people did not think of MM as an ‘English’ disease and found it difficult to reconcile themselves to the fact that they had developed a MM whilst in England and that in terms of skin care, their behaviour at home and abroad should be the same. Steve who had worked as a manager in the Middle East for many years was one of the people who emphatically expressed this viewpoint. In the following extract he discusses why he was finding it difficult to adjust to a MM diagnosis in England.

Steve So now I am learning that maybe I should get a barrier cream to put on. I don't know so I am not sure, this is one thing that bothers me about this, about this sun cream.

Idah yes?

Steve I've never had it, I have never had it I always assume..... what should I say..... I don't, I would hate to think I wasn't sort of implying to you but from the point of view that the country you are....what should we say..... naturally born in

Idah Yes that you are native in

Steve you are a native of it and in your case, your skin pigment should protect you from the sun in South Africa.

Idah Perhaps....

Steve And I think well okay, err I don't think I can ever imagine I could be bothered with the sun in this country, I know I am because I know I used to go on holiday as a boy and sometimes I would blister and peel if I was exposed to the sun for a long while that was in Devon where we always used to go as a boy, so I don't know I always think I was always under the impression one would have to take these [sunscreens] when one was in a foreign country which was alien to your environment, which you were not a native of it

Idah I see what you mean, yes, I do see what you mean

Steve So I find it very hard with this, this having to apply it here in *England*, anywhere else yes but *here*?

Idah So when you were in X [the country he was in] did you apply sunscreen?

Steve I didn't! (both laugh) I should have done and I never did. But yes in Saudi I was entirely at fault for not applying this erm cream

Like Steve, others in the study had also found it difficult to behave the same in England as they did when they were abroad. Most had enjoyed foreign holidays and described themselves as being 'careful' when they were abroad by applying sunscreen and taking other precautions like wearing wide brimmed hats and long sleeved loose fitting cotton clothes. In England, however, they did not expect to burn because of the 'miserable

weather' and therefore did not take the same precautions. Even the English summer sun was not perceived to be as dangerous as the sun in other places. Most confessed to risky behaviours like not applying sunscreen and wearing shorts and sleeveless tops when they were outdoors especially in the cooler months or when it was overcast. However, as Lisa a 36 year old office worker learnt, it is still possible to burn even when it is overcast in England

Lisa My friend and I went to Skipton for the day like and there was no sun, it was overcast, you know, so I didn't bother with anything like that. We just walked around, went in the shops and did various things, then went back home. Later I was getting myself ready for the evening meal, under the shower, and I found that I had got blisters on my shoulder. I had blisters on my shoulder and I could feel them (rubbing her shoulders) and I thought 'ooo that's sore, that's sore' you know? I had burnt when there wasn't even any sun! Who would have thought it was possible? Well that taught me a good lesson, and with the cancer, now I cover up all the time

Since MM was not considered an English disease then risky actions taken in England were not perceived as dangerous. Some of the most interesting insights into why individuals did not perceive themselves as being at risk of MM were yielded by the questions in the interview guide around lifestyles and hobbies (see appendix 6 for interview guide). How people viewed what they *did* in England showed the gaps in their knowledge about MM and revealed erroneous beliefs about causation. For instance very few people admitted to sun bathing and some, especially among the older ladies, declared that they did not 'like' the sun. There appeared to a wide spread belief that in great measure sun bathing, broadly defined as *sitting* out in the sun, was dangerous and was the cause of MM whilst other activities, albeit the fact that they were done in the sun, were not harmful. A few examples of this perception are presented below.

Julie I don't sit out in the sun, never have, but oh I do enjoy a spot of gardening. And really that's the only time I am ever out in the sun.

Clive I'm not a sun worshipper, as you get people, I love the sun yes, I like to be out in the sun, I mean I prefer to go walking rather than sit in

Chris I can't believe those young girls who just sit out in the sun, waiting to roast! I mean don't get me wrong, I do believe being outdoors is good for one and I often go out a play a bit of soccer or golf during the weekend to let off steam

Dave Hobbies you say? Erm.... now let me see....erm hobbies? Now I'm not sure, reading I suppose. What are my hobbies? That's a difficult one (laughs) erm would you say cycling was a hobby?

Idah Yes I suppose I would

Dave I look at it more as a way of keeping fit but okay yes, I enjoy cycling

Paul Yes trying to do my bit for the environment I guess, so I walked there [to his GP's surgery]. When I don't cycle I walk you see.

Idah You walk and cycle?

Paul Mmm, we do quite a bit of walking, as much as we can, or go out on our bikes, but we haven't been out this week anyways- its so bad [the weather] but when it nicer, I cycle from job to job, get my vitamin D in that way

Although the activities described above where performed in the sun they were not regarded as being risky. It was almost as if *doing* something outdoors was sun proof as few seemed to adequately protect themselves whereas just *sitting* in the sun was perceived as dangerous. In a nutshell, people who sat out in the sun, mainly abroad but also in England were perceived as the ones at risk of getting MM but other activities such as working in the garden and walking did not count as 'sunbathing' and therefore were not risky.

At this juncture it is important to state that this phenomenon was only observed in about a third of the sample and can not be generalised to all the study participants. Unfortunately the limited number of studies on presentation delay in MM done in England makes it difficult to know whether this perception that being in England is not a significant risk

factor for MM has been observed elsewhere. The researcher has failed to identify other studies that have reported this observation and it would be interesting to see if other studies would yield the same results.

### 6.3.3 OKAY I KNOW ABOUT MELANOMA BUT I AM ONLY 43

Age also played a role in how individuals perceived their risk of getting MM. Knowledge about ‘cancer’ was wide spread but sometimes individuals did not associate their knowledge with their own personal risk. In his study of rheumatoid arthritis (RA) Bury (1982) found that younger patients with RA often completely misinterpreted their symptoms because they ‘knew’ that RA was a disease for the elderly. Bury’s conclusions find resonance in this study. As Frank, a 43 year old man who ran his own small business, stated after being asked about his knowledge of MM

Frank Okay I knew about melanoma but I was only 43 and 43 year olds don’t get melanoma (laughs) or so I thought

He went on to describe how he had observed a mole on his arm changing for about 10 months but had not felt inclined to do anything about it because he ‘knew’ it was not skin cancer. His convictions were further strengthened by the fact that his grandmother had had MM when she was in her eighties and therefore that was simply not him. Like Frank other young patients also expressed surprise at being diagnosed with MM especially Colin the youngest participant in the study. Although 23 year old Colin had not actually delayed in seeking attention for his symptoms this was mainly because of pressure from his mother who was a nurse rather than because he had suspected MM.

Colin Coming back from Spain I’m nice and brown yeah, and really pleased and am helping the old man in the garden when my mum comes out and says ‘whats that on your back?’ I think its like nothing yeah but for like the next week she keeps on at me and even makes an appointment at the doctors for me coz she works there! I

go grudgingly to shut her up and he cuts a piece out and I think that's the end of it when he rings me and its like wow I have cancer

When asked, as were all the participants in the study, to describe someone they would predict as being at risk of developing MM, the younger participants in the study described aspects of the archetypical candidate with fair skin, maybe older who had spent a life time burning in the sun but none of them identified MM as the second most common cancer in the 20-39 age group. Although a significant body of evidence relating to denial in accepting oneself as 'someone who gets cancer' exists, what these participants were describing was not so much denial as simply not perceiving themselves as being at risk of MM because of their age. Interestingly the converse is true of some of the older participants who were not surprised to get a MM diagnosis because of their age

Luke No it didn't affect, I didn't go into deep shock or trauma. No it didn't affect me at all, no. Mind you I suppose really I am an old man I'm 76

Idah Are you?

Luke Oh yes! I've got er, I must admit, you know (laughs) I suppose that one expects all these sort of things, but erm no it didn't affect me. I heard someone say the other day, when you get older (laughs) someone said, there is one thing about being old you have got plenty to do. You've got to see the doctor, see the chiropodist, see the dietician see and so on (both laugh).

Winne At my great age everything starts to fall apart anyway so this skin cancer thing was just another one of those things

Unlike the younger participants who had delayed in seeking attention for their lesions because they did not expect to get MM, some of the older participants delayed because they actually *expected* to get 'all sorts' with increasing age and were therefore not alarmed by the symptoms of MM. Kiki, a 62 year old woman illustrated this point when recalling why she had not attributed her symptoms to MM. Her account illustrates the perception,

shared by many older people, of declining health with increasing age (Wright and Bramwell 2001; Evans and Richardson 2003).

Kiki On the day I turned 50 every ache and pain and freckle in town decided to come along for a ride and has never left! So erm when this mole I had had for about... mmm well, I would say maybe 10 years started to grow bigger and a bit you know, browner, I thought nothing of it, I had so many other new ones anyway. It was only when it started bleeding and not healing that I thought now wait a minute

In a study of the signs and symptoms of MM in older populations, Christos et al (2000) reported that like Kiki, Luke, Winnie and others in this study, older people are less likely to seek attention for earlier signals of MM like changes in elevation or colour of their lesions, but more likely to report bleeding and ulceration; symptoms associated with advanced disease and poor prognosis. This is probably because they perceived the growth and changes in their moles as a normal occurrence of growing older and it took more severe symptoms like persistent bleeding and ulceration to alert them that their symptoms were more than the expected 'growing pains'.

#### 6.3.4 I MAY HAVE BURNT AS A CHILD BUT SO WHAT?

The final reason for low risk perception that led to misinterpreted symptoms discovered during the study was associated with participants' life history of sun exposure. Although epidemiological studies have identified sun exposure in childhood as the major risk factor for the development of melanoma later in life (Whiteman et al 2001), most of the research participants did not know this. Most knew that MM was linked with sun exposure but in terms of aetiology could go no further than this. Not surprising, because of their skin type all the participants recounted occasions during their childhood when they had burnt, some more frequently than others. From their accounts it would seem that wearing sunscreen is



a fairly modern phenomenon as few described their parents applying any on them and most confessed to only becoming more aware of the importance of protecting themselves from the sun when they were older. Hugh, a 46 year old professional, gave one of the most vivid descriptions of sun exposure in childhood. Although he had been born in England his parents had migrated to a country in Southern Africa when he was four years old, only returning to England when he was a teenager. According to his account he had spent most of his childhood running about topless in the hot African sun without any sunscreen or any other form of protection because ‘in those days it didn’t really matter’.

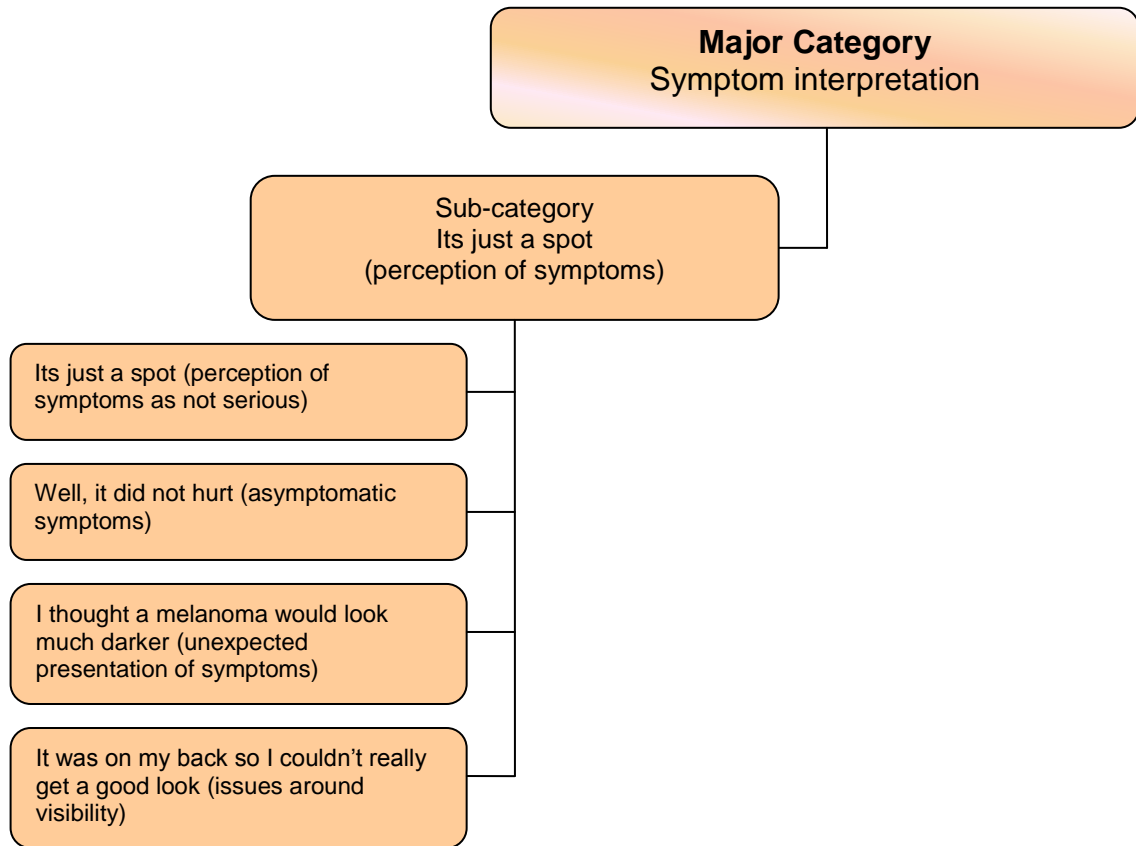
Hugh I honestly can not tell you how many times I burnt as a child. I was always burning, always bright red. I now understand from X [skin cancer CNS] that erm burning, exposure in childhood contributes to these things but for me I’m afraid it is too late. I have considered the possibility of suing my parents for negligence (laughs)

Hugh’s account brings to light an important contrast- sun exposure as a child versus sun exposure abroad. Due to their limited knowledge of MM aetiology, it was not surprising to note that participants did not connect episodes of sun burn in childhood with their symptoms now. On this account, it inevitably meant that symptoms were frequently misinterpreted and help seeking delayed. More surprising, however, were those who had spent time in warmer climates where the sun’s rays are more intense than in England when they were older but did not seem to consider themselves to be at a higher risk than the others. In this instance, blending research approaches might have been advantageous in order to quantitatively measure how individuals who had lived abroad perceived their risk when compared to those who had not. However, because the study used qualitative interviewing it is only possible to make inferences based on what the participants said.

Several participants had spent time in warmer climates in various capacities. Matthew had served the military in Northern Africa ‘during the war’. He had met his wife there and decided to stay and operate tours for tourists. This he had done for 17 years before returning to England. Others to spend considerable time abroad included Simon, a professional who had spent several years working on a project in Southern Asia, Len who had spent a decade of his life in several African countries, John who had spent a few years travelling across Asia doing voluntary work after school, Steve who had worked in the Middle East for many years, Lulu an ‘army wife’ who had spent some time in the Far East. Luke (interview 4) and Dave (interview 30) had worked for the armed forces and had spent many years abroad in different locations as part of their tours of duty. Why these individuals whose life history of sun exposure immediately placed them ‘at risk’ of developing MM did not perceive themselves to be at risk might be explained by the fact that they failed to make the connection between their symptoms and what they knew about MM, or perhaps they were optimistically biased or maybe, as will be discussed next, their failure to recognise their risk was directed by how they perceived their symptoms.

## 6.4 ITS ONLY A SPOT

Figure 6.3 Perception of Symptoms



In trying to understand why participants had ‘delayed’ I was struck by how in their accounts of the months preceding diagnosis participants demonstrated a passivity or lack of urgency about their symptoms. They had been slow to go to the doctor and for many, symptoms were not perceived as important enough to warrant making an appointment. As I continued the process of constant comparison it became more apparent that how people perceived their symptoms was a crucial factor in whether they presented for diagnosis and treatment. The following memo was written after the sixteenth interview with Martin a 47 year old man who had a 7.8mm thick lesion. This interview was particularly informative

and the memo is an illustration of how I was able to ‘catch my thoughts’ (Charmaz 2006 p72) and crystallise the direction I was going to pursue.

What is happening here? Everyone talks about symptoms so symptoms are definitely central to how and when people seek help for MM.\* **Symptoms major theme of study?** But even as they talk about their symptoms very few seem to *realise* the importance of the symptoms they are describing. They seem too casual, too nonchalant about something that had the potential to actually *kill* them. Some (Paul, Matthew, Eddy, Joan and Martin) pretty much apologised for going to see the doctor! Martin is fortunate that his MM had not begun to metastasise but listening to him you would not think he was someone that was close to danger. He seems to dismiss his mole as nothing important. Could it be that he does not realise, does not *perceive* (discern, appreciate, apprehend, comprehend, deduce, realise) the true nature/significance of his symptoms? While the symptoms themselves are important this *perception of symptoms* seems even more important. I am beginning to think that it is not the symptom itself but what someone *thinks* about it. Having a symptom alone is not enough, clearly someone has to *see* that it is actually a symptom otherwise nothing happens. But what is preventing people from *seeing*? They are not stupid so it must be the symptoms themselves. I think it’s the nature of the symptoms. The way they present (insidiously, innocuously). I believe if the moles bled profusely, were terribly painful, or really big people would seek help sooner. I think the patients do not perceive the seriousness of their symptoms because of the nature of the symptoms. Seems a bit obvious but need to strengthen claim that nature of symptoms influences how they are perceived which in turn influences help seeking behaviour. Add question about nature of symptoms to interview guide. ‘Can you please describe your lesion/mole to me? Can you describe the characteristics of your MM to me?’ **Possible major category.**

One of the central tenets of the GT methodology is that extensive literature reviews are often conducted after developing an independent analysis. Accordingly, after writing this memo I conducted a literature review on the impact of symptom perception on help seeking behaviour. This review revealed ample evidence in the literature to support the claim that people do not simply respond to the presence of the symptom per se, but rather consider the *nature* of the symptom and what it might indicate (Goldsen et al 1957; Rosenstock 1974; Bishop 1987; de Nooijer et al 2001b; Smith et al 2005). Findings from the study offered further support to this argument. In this context, however, the nature of the symptoms experienced, rather than prompting individuals to seek assistance often

prevented them from doing so. The following pages report findings from the study illustrating how and why the nature of the symptoms experienced contributed to patient delay in seeking medical intervention.

#### 6.4.1 ITS JUST A SPOT

In Antonovsky and Hartman's 1974 review of all cancer types, a high percentage of the studies reported that patients did not realise the significance of their symptoms. 30 years on there seems to be very little improvement in this area as across a broad range of types of cancer, including MM, study after study has shown that one of the greatest impeding factors in the process of interpreting symptoms and inferring illness is the attribution of possible cancer symptoms to other common ailments. Lamentably the findings from this study are no different. Although patients observed the changes, they failed to correctly interpret them and attributed everyday occurrences to explain them. During initial coding one of the first codes created was 'alternative diagnosis' and as analysis progressed it was interesting to observe how individuals labelled their symptoms. The 'alternative diagnoses' given to explain symptoms ranged from common moles, marks, spots, freckles, acne, to normal changes that occur to the skin as a result of ageing. Even those who said they thought it was 'nothing' probably meant that they were not alarmed by their symptoms because they perceived them to be 'normal'. Sue, the first person to be interviewed during the study told of how she thought the spot on her back was caused by a metal allergy brought on by her bra, even though she later admitted that her bra fastenings were usually plastic. The certainty that her symptom was 'just a spot' made it difficult for her to justify going to the doctor.

Idah Did you have any idea what it was?

- Sue Oh yes, very much so, well I thought so even though it turned out that I was, er, blind to the effect as to what it was. You see I'm allergic to metal and I always thought this spot on my back was caused through me bra, at the back so I didn't think anything about it
- Idah So you did not think anything of it because you thought it was caused by your metal allergy?
- Sue Yes because with being allergic. The funny thing is I developed a tendency to pull it down [demonstrates pulling the bra down] to keep it away from the spot because it irritated it a bit and I have always done that, never thinking anything toward at all, never thought nothing about it
- Idah I see, so what made you realise that it was not nothing?
- Sue Well (laughs) er how I ended up starting the ball rolling was I had been down at my son's and I was doing just what I demonstrated to yah, pulling it down and my son said 'whats up with you mother?' jokingly, Haven't you had a bath today?', you know and I said 'don't be cheeky, I've got a spot on my back' 'Do you? Lets just have a look at it' and then his wife had a look and she says 'how long have you had that?' Oh, I said, I've had it ages, its only my bra that's causing it, so she said 'well, have you been to the doctors with it?' and I said 'well, no because not for a spot', I said, 'it will clear up'. 'You want to go and get it checked out' she said. And then, my own daughter, she made a comment and I said 'would you like to have a look at this? X [daughter-in-law] said I should go to the doctors with it' 'Yes mother, you certainly should' 'But why, its only a spot' ' yes I know but its red and inflamed' 'Oh is it? Alright'

Like Sue, for many knowing what was 'normal' and knowing what was reasonable or bad enough to warrant making an appointment was an issue and they worried that they might be wasting the doctor's time and be criticised for it. It was only when her daughter told her that her 'spot' was red and inflamed (more serious than she had previously thought) that Sue decided to visit the doctor. These findings are in line with Andersen et al's (1995) observation that patients are more likely to consider their symptoms to be caused by normal life circumstances than by cancer, inadvertently leading to longer periods of delay. For example, Koldjeski et al (2004) found that some women, later diagnosed with ovarian cancer, did not associate symptoms like abdominal bloating, indigestion problems, fatigue,

vague abdominal pain and weight loss with cancer as they are more commonly associated with generalised non specific minor illness and valuable time was lost while they engaged in self-treatment practices.

The literature reveals a general tendency among the general public to give little attention to mole surveillance and other indications of MM. This was highlighted by a study conducted in Southern Italy in which moles and freckles were interpreted as ‘common’ and not really significant (Montella et al 2003). This perception of moles as insignificant and common was widespread so much so that one participant expressed surprise that his MM had been caused by a mole.

Charles        I had heard of skin cancer but I never imagined this would be skin cancer. I don’t know what skin cancer would be but I would always imagine that you would have say a sore place on your arm through over exposure to the sun, which would cause the cancer on the arm, something would happen to it and this would be the skin cancer. But skin cancer with a *mole* erupting and I find now err I think part of the research that cancer UK are doing is where the.....erm connection is between skin cancer itself and the mole. Why does a mole suddenly erupt?

As they thought their symptoms were insignificant only a few respondents remembered thoroughly scrutinising them. Some did not even remember labelling them and as Donna, a 29 year old health worker, phrased it ‘it just happened’. Like many perceptual processes, labelling symptoms appears to have occurred on an unconscious level as illustrated by this excerpt from an interview with Len a 59 year old manager.

Len        I can’t think of anything apart from showering and feeling this..... thing and wondering what it was, well not even wondering what it was, one thought it was, you know kind of unconsciously, I donno probably some sort of er.... what shall we say pimple or boil or something that had ruptured and formed a scab and er I think at one stage, I cant remember thoroughly but I think the scab fell off at one time and came back again.

Since all the patients had ultimately decided to seek medical help it follows that ‘something’ must have made them realise the true significance of their symptoms. This ‘something’ (triggers for action) will be discussed in the next chapter.

#### 6.4.2 WELL IT DID NOT HURT

Another reason why participants in the study failed to recognise their symptoms as MM and subsequently delayed in seeking attention was the asymptomatic nature of some of the lesions. Unfortunately many melanomas that have not already metastasised are completely asymptomatic. During their study of 250 melanoma patients in South Africa, Krige et al (1991) found that in the early, and curable, phases of biologic evolution, the signs of melanoma are often subtle and provide few cues that arouse suspicion or alarm the patients. Not seeking help at an early and easily curable stage of disease and waiting for more advanced symptoms was a common feature of this study. Like the patients discussed in other studies examining presentation delay in MM (Blum et al 1999; Richard et al 2000; Montella et al 2002; Negin et al 2003) some of the patients in this study sought medical attention only after they had noticed ulceration, bleeding, the appearance of a lump on the pigmented lesion, skin breakdown, pain and itching – late features in the progression of melanoma. When lesions appeared ‘quietly’ (Richard et al 2000) with the absence of systemic signs, delay was more likely to occur. It would seem that symptoms providing well-defined and strong sensations are more likely to lead the patient to conclude that something specific is wrong and shorten the delay period. On the other hand, vague complaints or weak and varying symptoms are harder to define and interpret. This may inadvertently lengthen the symptom evaluation and response time. The following extract



is taken from an interview with Matthew a 66 year old man and is an illustration of how patients in this study typically reacted to the detection of unexplained symptoms.

Idah                    When did you first notice, was it a mole you first noticed or what was it?

Matthew                No it was a mole, it might have been there for years I have never noticed it. But one particular time I think I was getting out of the bath one time and I was drying myself and I thought, it was a funny edge, it was about the size of that [showing his thumb nail], it had a little red edge on it. It was a different colour to the rest of the mole. And that was what set me thinking and I had heard so much on television and in the papers about people having mostly sun tan moles and I thought well, that cant be because the only time I wore shorts was when we were in service overseas but that's war time you know, a long time ago. I couldn't understand why I hadn't notice it before.

Idah                    So what happened next?

Matthew                Well nothing really. It was so fine, it was just a little red edge on it.

Idah                    I see. So you knew it was there and had a little red edge on it. Was there anything else about it? Was it raised or growing bigger or itching perhaps?

Matthew                I suppose it was a bit raised coming to think of it, a little bump maybe but I can't be certain. It didn't itch or anything so I just let it be

Idah                    You seem to have been quite relaxed about it, so what changed? What made you go to the GP?

Matthew                It started bleeding. Not lots of blood mind but all the time like. It got to a point where there were always blood on the sheets in the morning and bits of blood on my shirt and that made me think something was definitely wrong and made the wife send me off to the doctors cause she getting tired of washing blood stains off the sheets and me shirts.

In their study on detecting cancer symptoms and seeking medical help de Nooijer and colleagues (2001b) demonstrate that reacting to symptoms like Matthew did is not unusual. Patients, it seems, are often not worried at the initial moment when they discover an abnormality. However, when symptoms do not disappear spontaneously, when symptoms get worse or when additional symptoms appear, they realise that that something

could be wrong. Clearly the reaction to the detection of symptoms seems to be governed by the patient's perception of the nature of the symptoms leading either to shortened or prolonged appraisal delay (Andersen et al 1995). For example while Matthew was not alarmed by changes in the circumference and colour of his mole and was only steered to action when it started bleeding, Jane a 55 year old community health worker was uneasy about her mole the moment she noticed it had grown.

Jane I just knew something wasn't right. I take growing moles very seriously.

Jane had reacted immediately and made an appointment with her GP who had assured her that the mole was benign and ultimately this false assurance by the doctor led to her delay. The issue of doctor induced delay will be considered further in the next chapter (see section 7.1.4). The difference in how Matthew and Jane perceived their symptoms may be explained by their different levels of knowledge about MM evidenced by the answers they gave to the following question.

Idah Before you were diagnosed with MM, did you know anything about it?

Matthew Well, sort of....

Jane Yes, quite a lot actually, I mean I knew about it already but a couple of years ago we did a bit of a melanoma awareness campaign at work in the summer so that really helped my knowledge along

Jane was clearly extremely knowledgeable about MM whereas Matthew's response showed that his level of MM knowledge was not as high. As such their differing reactions to their symptoms were governed by their perceptions of the nature of the symptoms which to a large extent was influenced by their levels of knowledge.

Some people delayed getting care for a long time, sometimes weeks or months, because they were not experiencing pain. This factor is potentially very important because pain is not a major symptom of many serious diseases, such as hypertension. Pain is also not one of the main warning signs of cancer. Many expressed shock at the diagnosis of MM- of cancer- primarily because 'it did not hurt'. The research participants made comments like

Steve            I couldn't believe I had cancer, I mean it didn't hurt at all

Donna           Before she [the doctor] told me I had malignant melanoma I had never felt better! I had just started going to the gym for crying out loud, I mean I felt *no pain* [emphasis supplied]

Kiki              You know that if you have cancer your life is going to be shorter than everybody else's. So I suppose it was a surprise that I did have cancer but I was not hurting or sick

Ian                All of a sudden they tell you that you've got something that's potentially life threatening and you're thinking so where's the pain?

The underlying implication of these statements is that the individuals expected to have pain and possibly feel unwell because they had cancer. However, as with most other cancers, pain is not one of the main warning signs of MM. If early presentation to the doctor is to become a reality people need to know what the symptoms of serious diseases are and realise that some illnesses do not have the signs people often rely on in deciding whether to seek medical care.

#### 6.4.3 I THOUGHT MELANOMA WOULD LOOK MUCH.....

20 years ago Bishop (1987) proposed that people have pre-existing notions of the symptoms associated with common illnesses and self diagnose by comparing the symptoms they experience with those they expect for a given disease. Leventhal et al (1984) suggest that responses or behaviours in an illness situation are determined by a

person's mental representation of an illness. Thus when symptoms present as expected, for example a lump in the breast in breast cancer (Burgess et al 2001) or severe chest pain in myocardial infarction (Horne et al 2000) individuals tend to take immediate action. Unexpected and ambiguous symptoms however, are harder to define and interpret. It became clear during the course of the study that MM symptoms often fall into the 'unexpected and ambiguous' category. Only three participants in the study had ever encountered a real melanoma so for the rest of them the mental representation of what a melanoma looked like was shaped by posters in the doctors' surgery, images on television or the internet, stories reported in the popular literature such as *Cosmopolitan*, *Readers Digest* and imagination. When asked what they had expected MM to look like, most described 'black' 'very dark' 'hideous' 'unsightly' 'painful' 'bleeding' 'big' 'large' and 'raised' lesions that no one could possibly ignore. The descriptions offered below by June and George are a general reflection of what participants in the study expected MM to look like

June            I had got a leaflet up in my bedside draw with pictures of malignant melanomas which were sort of raised nobly things, crusty things, things that bleed

George        Oh yes definitely black and ugly, angry looking, I mean when you think of cancer, its not some little mole gone bad

In reality, as discussed in the previous section, most melanomas initially presented as innocuous unsuspecting lesions and this meant that expectations were not matched by experiences. In fact even after diagnosis most felt they still would not be able to distinguish a MM from a common benign lesion.

Ian            Mr X [the surgeon] actually took a picture of it and showed me on a digital camera, but I couldn't say it was, it looked any remarkably different to things that I had got on any part of my body that and yet he recognised it straight away. So it is

very difficult to differentiate between what is a melanoma and what's just a freckle or a raised mole or a wart.

Although this study was not designed to identify the sources of expectations, there is a definite need to identify factors that influence the development of inaccurate representations. For example, June a 60 year old mother who was a full time carer for her autistic son was one of a number of participants who read information leaflets and looked at posters in her local medical centre. She describes the pictures of MM on posters as vivid and eye catching and definitely not matching her own melanoma

June Well I suppose they have to do it [show dramatic pictures of MM] for effect, but all the pictures I have seen of skin cancer usually look quite frightening, dark horrible erm, what's the word...ulcers? Anyway whatever it is, those pictures look nothing like what I had

June went on to say that if her symptoms had matched the pictures then she would have sought medical attention sooner. Of course these words were said with the benefit of hindsight and can not be taken as fact but they highlight the importance of examining education materials provided to the general public carefully to identify the impact they may have.

#### 6.4.4 IT WAS ON MY BACK

There is much debate in the literature about whether lesion visibility has an impact on presentation delay with some arguing that patient related delays are not longer in visually inaccessible lesions than in visible ones (Doherty and MacKie 1986; Rampen et al 1989; Krige et al 1991; Richard et al 2000). Others (Temoshok et al 1984; Schmid-Wendtner et al 2002) dispute this claim arguing that their studies have found an association between longer presentation delay and lesions in visually inaccessible areas like the lower and

upper back. At least one study (Montella et al 2002) offers a different perspective and argues that lesion visibility (as opposed to invisibility) is associated with major delay in seeking medical assistance, since progressive changes are less alarming than the appearance of a new lesion. To further complicate the debate, there is also uncertainty about whether tumour thickness tends to be higher in visibly inaccessible lesion. Ironically, despite reporting that anatomic site had no impact on delay, in a large study of 590 patients conducted in France, Richard et al (2000) found that tumour thickness tended to be higher in melanomas that were not visible. This finding was not confirmed by Temoshok (1984) whose investigation into the factors related to patient delay in seeking medical attention for melanoma indicated that prognostic indicators such as tumour thickness were not significantly different in hidden or visual lesions. This variability of findings is unsurprising given the varied nature of sampling, methodology and measurements employed by the different studies and further highlights the need for more research to conclusively determine whether lesion visibility has an impact on presentation delay.

As discussed in the first chapter of this thesis the distribution of MM on the body varies by sex with over a third of male cases arise on the trunk of the body, particularly the back, while the most common site for females is on the legs (Cancer Research UK 2006). This probably compounds why men appear to be more likely to delay seeking help for their symptoms. Research has repeatedly shown that men are less likely to notice symptoms and it is unsurprising that only two women in the study compared to seven men indicated that one of the reasons they had delayed in seeking attention for their symptoms was

because their lesions were visually inaccessible. The first woman, Kiki, had mild arthritis and therefore found it difficult to examine the mole that had developed at the back of her leg and the second one Samantha, only sought medical advice after a friend noticed a dark mole at the back of her thigh whilst they were on holiday. All seven men had developed MM on their backs and made comments like the following two:

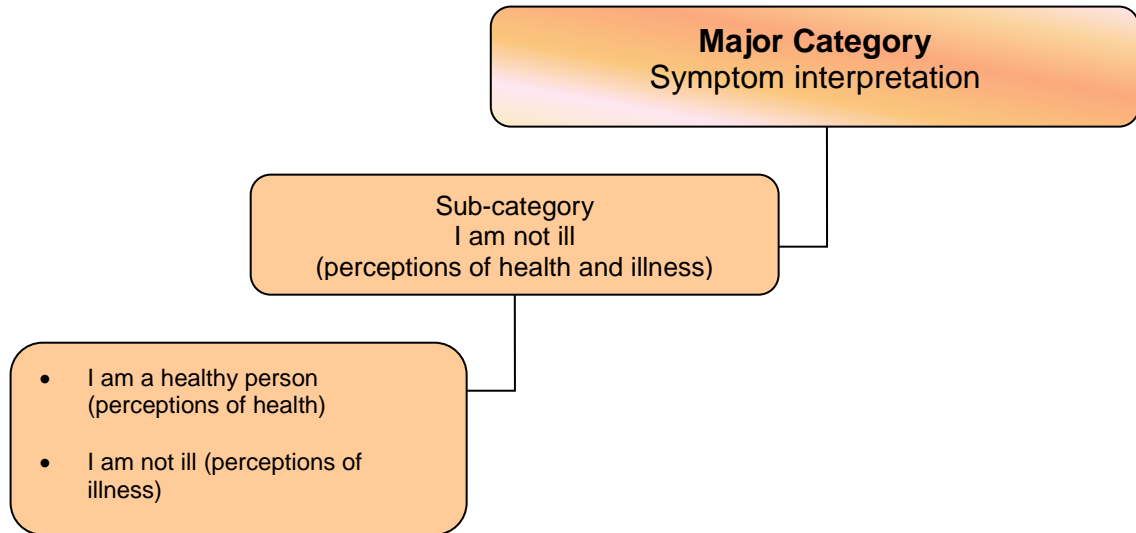
Steve            I think actually it's the placement of it. Maybe if it was more visual I would have noticed, and done far more about it. So I suppose not being visual was the thing that came as a surprise to me that it was a malignant melanoma.

Dave            It is very difficult if you have anything on your back because you can't eye ball it yourself.

In the light of these observations and the contradictory nature of the evidence available, it is apparent that more research is required to determine the true impact of lesion visibility or invisibility on presentation delay. As will be discussed in the recommendations presented in chapter nine, this information can be used to tailor health promotion initiatives to target groups, such as men, identified as being at an increased risk.

## 6.5 'I AM NOT ILL'

Figure 6.4 Perception of Health and Illness



The final determinant for the misinterpretation of symptoms identified by the study was how individuals perceived their health and illness. Participants in the study repeatedly referred to themselves as 'healthy' and took great pains in stressing the fact that they were not 'ill'. This led me to wonder about what is meant by the terms 'health' and 'illness'. In my perception these individuals were (or at least had been) ill. They had each received a positive MM diagnosis and undergone treatment for it. So why did they not perceive themselves as ill and what made them claim they were healthy? One of the greatest strengths of the symbolic interactionist perspective used in this study (discussed at length in chapter 4, section 4.2) is the emphasis it places on trying to understand the world as it is seen by the research subject. It focuses on how people define events and reality and how they act according to their beliefs. As such, in order to understand why the research participants perceived themselves as 'healthy' and not 'ill', it was crucial to have an understanding of lay beliefs about health and illness.



One of the first studies to explore the way in which people define health and illness was undertaken by Herzlich (1973). The study was based on interviews with a sample of 80 people, drawn mainly from middle-class backgrounds and living in Paris or Normandy. Herzlich discovered three distinct dimensions of health embedded in the accounts of the interviewees. First, there was what she termed 'health-in-a-vacuum', that is a view of health as simply the absence of illness. Illness, in this context, is defined as 'subjective unwellness' (Sarafino 2005), the subjective interpretation of problems that are perceived as health related (Scambler and Scambler 1984) and the personal experience of bodily disorder and feelings of pain and discomfort. Illness can thus be distinguished from disease which is often endowed with an 'objective' quality (Clarke 2001) and refers to an abnormality in the structure and function of body organs and systems. 'Disease is something an organ has: illness is what a [human being] has' (Helman 1981 p.544). In short, illness is about how a person feels and has been defined as 'the human experience of sickness' (Kleinman et al. 1978 p. 251).

Herzlich's (1973) dimension of 'health-in-a-vacuum' or health as the absence of illness prominently featured in the participants' accounts of why they considered themselves to be 'healthy' and not 'ill'. Health and illness were considered to be in a one-to-one relationship, one was often not distinguished from the other. If participants did not feel ill (were not unwell) then they perceived themselves to be healthy and equally because they perceived themselves to be healthy it meant they were not ill. An example of this perception were the following comments made by 68 year old Matthew

Matthew        To give it to you straight lass, the way I see it, you can't be healthy if you are poorly, healthy people are not poorly. If you are unwell and ill like then you are not healthy, is as simple as that

Matthew's account captures the mindset behind some of the comments made during the interviews- you have to be unwell to be ill. In this sense, the ability of patients to recognise their symptoms as cancer was made more difficult by the contradiction between their perception of cancer as an illness associated with physical deterioration and the fact that most patients, bar the problem of a changing lesion, had little or no alteration to their physical well-being throughout their illness experience.

The second dimension of health discovered by Herzlich (1973) was the 'reserve of health' approach. According to this interpretation health is defined with regard to the capacity of the individual to maintain good health. This capacity consists of two elements, namely physical strength and the individual's potential for resistance to illness. Herzlich labelled the third, and final, dimension 'equilibrium'. Respondents in that study described equilibrium in terms of feeling strong and having good relationships with others. Both these dimensions of health identified by Herzlich were evident in the participants' accounts of their health although they were not often stated as explicitly as the first dimension. Participants frequently equated physical fitness with health and being physically strong and having the strength to carry out activities of daily living was considered to be a sign of health. Illness was considered a threat when it interfered with 'life'. This was mostly observed in individuals who had co-morbidity. For instance Winnie who described herself to be in 'poor health' had angina, hypertension and what she described as a 'touch of arthritis in my joints'. Although she listed the angina,

hypertension and MM as part of the reasons she was in 'poor health' it would seem her arthritis bothered her the most because it interfered with her physical ability to carry out activities of daily living.

Winnie I would not describe myself as a 'well woman', that's what they are called nowadays (laughs) but you see I cope, although my son tends to disagree, he can be so meddlesome fussing and fussing, I cant cope with him but I can just about cope with everything else but the arthritis.....

Idah I see, why is the arthritis particularly difficult to cope with?

Winnie Because it interferes! It makes fiddly things impossible sometimes

Idah Fiddly things?

Winnie like buttons and bottle tops, honestly sometimes I despair, then I need X [her neighbour and friend] to come round. She, bless her, is really very good and says she doesn't mind but sometimes its so stupid, and so *humiliating*

Like Winnie, Luke also described himself as 'not healthy' and again it was not the MM that he cited when he spoke about why he was not healthy but his newly diagnosed diabetes

Luke No not healthy, I have diabetes which annoys I find annoying, irritating I have to keep to a strict diet, that, well that bothers me more than the melanoma

It would seem that to these individuals and others like them an illness had to interfere with some physical aspect of living to be given serious consideration; although it must be added that mental illness was not discussed and therefore can not be commented upon. Comments made by participants would suggest that MM was almost not regarded as a legitimate 'illness' because of its limited physical impact. The perception that health and illness were linked to physical strength and the ability to maintain 'good health' was further evidenced by the observation that when participants who described themselves as 'healthy and not ill' were asked why they perceived themselves to be so, their answers

focused on physical health-enhancing behaviours they performed such as exercise, healthy diet, getting adequate rest, using sunscreen, not smoking, and not drinking alcohol excessively. The more health-enhancing behaviours they performed, the healthier participants considered themselves. Since the MM symptoms did not initially fit into their perception of what constituted ‘illness’ and they considered themselves to be ‘healthy’ most participants delayed in seeking help.

## 6.6 KEEPS A WATCHING BRIEF ON SYMPTOMS

Another concept to emerge from the study that adds further texture to the data around presentation delay relates to what individuals do when they realise that their symptoms probably require medical attention. In a process they label as the ‘symptom experience’ Dodd et al (2001) describe how individuals appraise or evaluate symptoms, make judgements about their cause, severity and whether they can be treated. From this appraisal, they conclude, individuals respond to symptoms in one of three ways. First, they can infer illness and decide to seek medical attention. Second, they can respond by deciding the symptoms are not serious and therefore not worthy of medical attention and finally the individual may also decide to keep a watching brief on the symptoms to see if they will get any worse before deciding to consult a doctor, thus introducing delay. This third response referred to as the ‘wait and see’ approach in the contemporary literature is the focus of this section. The data from the study indicates that there was usually a period of rumination in the patients’ symptom experience often resulting in the decision to ‘wait and see’ how symptoms developed before deciding to seek medical help. The majority of the participants in the study indicated that they had, at some point in their experience,

taken a decision to 'wait and see' if their symptoms would go away or respond to over the counter creams or get worse before determining for certain that they were serious. It was evident in the accounts provided that the period of 'waiting to see what happens' lengthened the period of their help-seeking delay.

Waiting to see what happens was closely related to all the other concepts presented in this chapter because regardless of their reason for delaying participants tended to keep a watching brief of their symptoms before making the decision to seek medical intervention. As illustrated by the symptom interpretation diagram (Figure 6.1) this concept can almost be described as the last hurdle or obstacle before the patient finally sought medical intervention for their symptoms. The 'wait and see' approach is well documented across a wide range of conditions from nocturnal enuresis and ear infections in children right through to myocardial infarctions and cancer (Zerwic 1999; Burgess et al 2001; Mason and Strauss 2004; Berry 2006; Spiro et al 2006; Ria and Kelly 2007). Regardless of the illness or condition, the general advice found in the literature is that this approach may not be in everyone's best interests and that medical advice should be sought promptly in order to avoid complications brought on by delay. Getting individuals to pay attention to this advice and present for diagnosis and treatment quickly remains one of the greatest challenges in health care. As Zola (1973 p.379) eloquently phrases it; 'Given the voluminous literature on delay in seeking medical aid for almost every conceivable disorder and treatment, we might well say the statistical norm for any population is delay'. How participants in the study finally moved from delay to action, from 'waiting to see what happens' to seeking medical assistance, will be discussed in the next chapter.

## 7. CHAPTER SEVEN

### SOCIAL ASPECTS OF DELAY

#### 7.1 INTRODUCTION

According to Stacey, sociology ‘constitutes a body of knowledge about societies and social relations within them and takes as its subject matter all areas of the social’ (1991 p. 13). As a consequence of this focus on ‘the social’ all aspects of human life are open to sociological investigation. It is the study of social behaviour that is at the very centre of the sociological enterprise (Clarke 2001). Explanations of human behaviour that are solely based on individual biological factors or psychological processes often can only provide a partial explanation for why individuals behave the way they do. From the point of view of the sociologist, human beings are essentially social animals and therefore a full understanding of human behaviour cannot be achieved without taking into account aspects of the social setting in which the behaviour occurs (Gabe et al 2004; Haralambos and Holborn 2004). In line with this assertion, this chapter gives an account of the social settings in which presentation delay in MM occurs. It presents the second major category of the study that examines the social contexts in which people live their lives and why certain behaviour (presentation delay) happen as a result.

It can be argued that symptom misinterpretation (discussed in previous chapter) is largely a psychological process in that it occurs internally. An individual can access and translate the meaning of their symptoms without consultation and arrive at a satisfactory decision. However, as Lee and Newby (1983 p.17) assert, ‘Sociologists have .... repeatedly rejected

the possibility of the totally isolated, non-social individual'. From a sociological point of view even the way an individual interprets their symptoms is shaped by social and cultural factors (Gabe et al 2004). In other words, the individual does not react to the symptom itself but to the meaning attributed to it (Freidson 1970; Zola 1973; Gabe et al 2004). In attributing meaning to an illness experience 'the individual sufferer does not invent the meanings himself but rather uses the meanings and interpretations that his social life has provided him' (Freidson, 1970 pg. 288). In this sense becoming ill is a social process that involves other people besides the patient. Zola (1973) maintains that the decision to consult a doctor is not simply based on how the patient interprets the symptoms but is also influenced by relatives, friends and work colleagues. Therefore, it can be argued that the decision not to consult, or delay consultation with a doctor is also influenced by social ties.

This chapter discusses the impact of social ties on the decision to seek medical intervention for MM symptoms. Figure 7.1, created from the findings of the study, illustrates contextual variables grouped under the umbrella of 'social aspects of delay'. These variables include 'is a busy individual'; 'is man'; 'is not comfortable visiting the doctor' and 'previous benign diagnosis'. The first part of this chapter will discuss each of these variables in turn. As shown by Figure 7.1 family, friends and significant others also play particular roles in the patient's help seeking experiences and these roles will be considered in the second part of the chapter. Despite the initial delay, all the participants in the study eventually sought medical assistance for their symptoms and the final section of

the chapter discusses what triggered them to finally take action or as one participant phrased it, how ‘the ball started rolling’.

### 7.1.1 IS A BUSY PERSON

All the participants were asked about their usual help seeking behaviour in relation to signs and symptoms. One particularly insightful answer was received from Paul a 40 year outdoor worker.

Idah    Aside from the MM issue, on a general day to day basis how often would you say you visit the GP?

Paul    Well not often if I can help it, I *am* a busy person, I have no time to be trotting off to see them every time I cough

The important issue to arise from this response was the fact that these individuals were indeed busy people and perhaps it was not surprising that they did not go ‘trotting off’ to see the GP ‘every time [they] coughed’ given everything else that was going on in their lives. As the interview progressed, Paul revealed that he was his ailing father’s main carer, the chairman of his local soccer club, an instructor at his son’s boy scout’s club, a part-time fire man, all in addition to his full time job and, as he joked, all these roles were his part time occupations but his real job was being ‘full time husband and father’. Hence the growing awareness of the almost tangible balancing act that the participants in the research had to maintain on a daily basis. Set within the context of both social and cultural circumstances this concept identified further properties that impinged on the participants’ decision to seek medical help for their symptoms at a specific dimension in time.



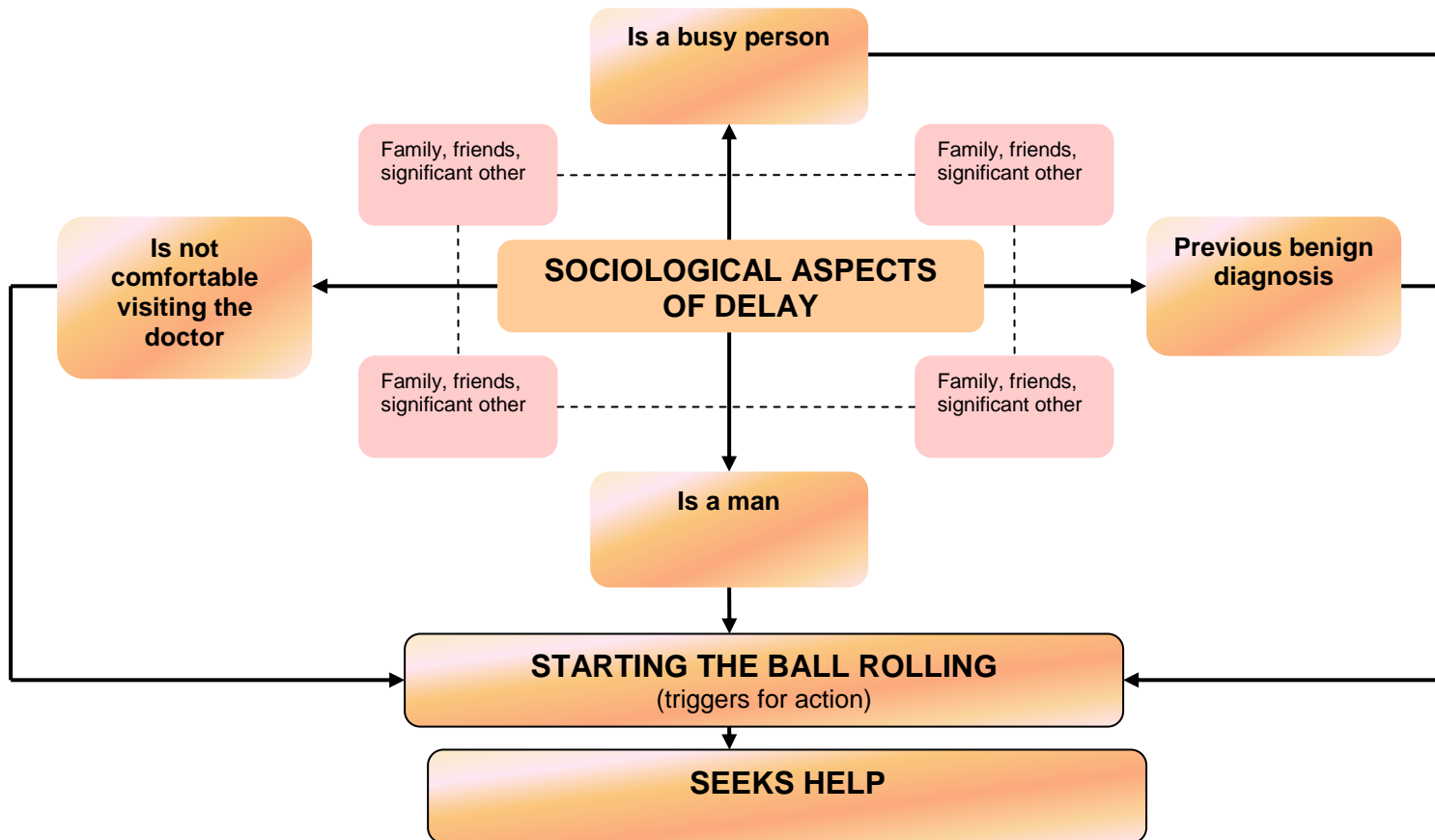


Figure 7.1 Social Aspects of Delay

In many ways the key tenet of this concept is the issue of time, or more precisely the lack of time. The causal conditions of this category relate to the participants as adults with life responsibilities and commitments into which the role of being a patient was required to adapt. These life responsibilities and commitments largely fell into three broad categories

- Social role demands
- Work commitments
- Comorbidity

Delaying help seeking as a consequence of perceived social role demands (for instance parent, spouse, employee) was a common feature of the participants' experience. Interestingly, although both male and female participants highlighted family responsibilities such as caring for children and elderly relations as well as household and business responsibilities as inhibiting prompt access to medical care, the roles articulated evoked early theories of the 'expressive' female and 'instrumental' male (Parson 1951). Instrumental roles are often economic and encompass assertiveness, independence, ambition and the need to dominate. On the other hand, expressive roles tend to be social and encompass sensitivity to the needs of others, altruism, warmth and co-operativeness (Bozionelos 2003). The results seemed to indicate that although women performed instrumental roles such as holding down demanding jobs, they were more strongly committed to expressive activities such as caring for children, men, elderly parents and each other than men. On the other hand, men were often identified as the 'breadwinners' of the family and seemed more committed to instrumental activities. Although they were less involved in expressive activities, they still assumed some of the expressive functions

of the family. Examples of how these ‘expressive’ and ‘instrumental’ roles affected help seeking behaviour will now be given

Devoting time and attention to the needs of someone else was commonly reported. For instance, stories like Julie’s, a 50 year old professional interviewed during the course of the study, seem to reflect the tendency of some participants to place the needs of others above their own. Julie had noticed that a mole she had had on her leg for about five years had grown and seemed to be changing shape. She had observed it for a couple of months and decided to seek medical attention. Shortly before she made an appointment her long term partner, after a lengthy period of speculation, was diagnosed with diabetes. He was extremely distraught and as his key support she had decided to put off seeking help for her own symptoms until his situation had stabilised.

Julie I know I sound like a bit of a martyr but he needed me at the time. I didn’t want to upstage him as in who is more poorly, so I decided to wait a bit, to give him time, you know? I knew I needed to get the leg seen to but then again I also needed to get him seen to as well

Idah Did he know that you also had concerns about your own health?

Julie Oh no, he would have insisted I go to the doctor otherwise and well, I think I sort of knew what it was, that it would keep

Knowing that they needed to seek medical intervention for their symptoms but being unable to do so because of competing priorities was a common theme that ran through many of the female participants’ accounts. Like Julie, June knew she needed to see a doctor about her symptoms but viewed caring for her autistic son as more important at the time.

June I knew that it wasn’t right but I didn’t think it was anything life threatening and I thought it could be left. And because I... at that time I cared for my son who has

an autistic spectrum disorder there were so many urgent things going off that I thought Oh next time I go to the GP I will just show it and check that there is nothing .

Idah So you put off going to see the doctor?

June Caring for my son seemed more important at the time, I didn't realise it would be malignant [malignant] melanoma I supposed had I thought carefully and read or gone on the internet my awareness might have increased but I didn't have the time to do that.

Idah So in the end what led to you going to your GP?

June I had to go to the GP usually once every four months for a review on medication that I am taking, and I thought 'Oh I will mention it one of those times I go to rule out that its nothing of real concern' and I think it was the third time that I went I just said 'that's nothing is it?' And he looked at it and he said ahh and he referred me straight away. I mean its not funny, I mean it is with hind sight but he immediately picked up that it could be very suspicious and he immediately referred me to Dr X (the dermatologist)

Work related demands were also suggested as receiving priority over discovered skin cancer symptom. Although men spoke of the financial implications of being away from work and expressed concern about the image they were projecting to others if they were absent from work due to ill health (see next section), for both sexes the issue of time was relevant. Apart from shift workers and those that had retired most of the participants worked 'regular' hours. These 'regular hours' typically stretched from about eight in the morning to about six in the evening, including the time it took to travel to and from work. Unfortunately it would seem that most GPs also work 'regular hours'. In addition, most GP surgeries were located near where the participant lived but their place of employment was often much further. This made it difficult for participants to be able to consult their GP during their 'free' time and they often had to make special arrangements specifically to see the GP which would explain why their visits were often limited.

Andy I mean I'm all for GPs working longer hours, everybody else has to so why not them? I mean with patient choice and all. As it is, getting to see one of them [GP] is a nightmare. I have to drive 30minutes from work to see them when they are open and even then they can't guarantee to see you on time, I mean last time I waited 20minutes and work kept calling because I was needed there as well

Nancy I have always worked and worked hard and worked 9-5 Monday to Friday, so if you need to go to the doctors you had to get time off work or book the doctors when you have got a days holiday or something like that, So I must admit going to the doctor I would leave it until the very last minute, I would have to feel that there is something drastically wrong before I went to the doctor.

Comments like these made by Andy and Nancy illustrate the challenges faced by working patients. As Nancy phrased it, she would have to feel that something was 'drastically wrong' before making the effort to see the GP. Since most participants did not view their symptoms as 'drastic' they tended to put off visiting the doctor until something they perceived as more pertinent demanded a visit to the doctor and then they used the opportunity to also have their MM symptoms examined.

Although co-morbidity can not be labelled as a 'life responsibility and commitment' in some cases it seemed to fit within the '*Is a Busy Person*' concept because of the demands having another illness or medical problem made on the time of those affected. It was not unusual to interview individuals who had other medical conditions apart from the MM. Indeed, for these individuals the MM was often perceived as the lesser of two or three evils because of its limited impact on activities of daily living, particularly in the initial stages. Apart from a day in surgery and occasional appointments, most people's lives continued relatively unhindered by the MM unlike other illnesses that some participants had such as diabetes, arthritis, chronic leg ulcers and chronic back pain that often

demanded constant attendance to the doctor or a change of lifestyle. By her own admission Lisa a 42 year old office worker had a demanding job and ‘probably worked too hard’. She noticed that a mole on her arm had grown bigger and darker at about the same time she discovered a lump in her breast. She made an appointment with her GP and they agreed to prioritise the lump in her breast. He urgently referred her for specialist care. She was diagnosed with an aggressive form of breast cancer, had a mastectomy fairly quickly after that followed by a course of chemotherapy.

Lisa From diagnosis it was very quick, I was diagnosed on Tuesday and I had the mastectomy on Friday. To be completely honest, I sort of completely neglected the mole. I knew it was there but it really wasn’t that important at the time. But the actual cutting out and everything wasn’t so bad it was when the chemo started it got harder. Hardest experience ever. The worst bit was the chemo. Maybe it worked on the skin cancer as well .....it was erm let me see erm maybe six or seven months afterwards, after I had finished chemo that I asked the oncologist to look at it [the mole] and he immediately called the dermatologist who agreed to see me that afternoon, so that happened quickly as well

Although Lisa had given her breast cancer symptoms priority over her MM symptoms the outcome was auspicious, others were not always so fortunate. Peter was interviewed just after he had taken early retirement from his job to care for his wife who had multiple sclerosis on a full-time basis. In addition, he had a complicated dental problem that required repeated visits to the dentist. He described how difficult the previous year had been for him trying to juggle all his commitments and priorities. He often had to take time off work.

Peter I could feel it. Yeah, when, when you’ve got one, and they’re a bit, you know, and it’s a bit rough, rough at the surface and, mind you, I didn’t know about all this business [the MM diagnosis].

Idah No

Peter You know what I mean? And then, it'd be 12 months ago. 12 bloody hard months. I didn't go to the doctor. I was getting a new dental plate and you see I didn't want to take more time off work so I left it. You know. I mean it was bleeding and my wife was dressing it

Idah it was bleeding and your wife was dressing it?

Peter We were dressing it but ... the, the bleeding never stopped.

Idah And how long did your wife dress it?

Peter Ooh, it must have been three or four months. She said it were like a little mushroom thing. 'Go down to the clinic', she said, 'they'll cut it off', they have a little surgery down at the, you know, doctor's. But then she got worse, much worse and I had take more time at work, you know

Balancing his social role as a husband, his work commitments and his dental health problems meant the mushroom like lesion on his back continued to grow unchecked. Although he knew he had to get it examined he delayed a further three months before making an appointment with the GP because he felt he was already taking enough time off work to care for his wife. When his wife was no longer physically able to dress his back because of her debilitating condition he was finally forced by the continuous bleeding of the lesion to go to the doctor. The doctor immediately referred him for specialist care and within a week the dermatologist had taken a biopsy of it. Unfortunately, due to the protracted period of delay, on excision the lesion was 9.6 mm thick and had metastasised. When he was interviewed, Peter was awaiting the results of a further biopsy of his lymph nodes to determine how far the cancer had spread. He was optimistic about his chances of survival. Four months after the interview I received a call from the skin cancer CNS informing me of Peter's death and instructing me not to have any further correspondence with the family. Disturbing as the story is, it painfully illustrates how delay caused by life's responsibilities and commitments can have a detrimental even fatal impact.

### 7.1.2 IS A MAN

Men are often portrayed as being unwilling to ask for help when they experience problems their daily living. Addis and Mahalik (2003) point to popular stereotypes of men being reluctant to ask for directions when they are lost, having difficulties in sharing vulnerable feelings with friends and family and avoiding seeking help from professionals as examples of their unwillingness to ask for help. In the context of this research, there is a significantly large body of evidence to support the school of thought that men are reluctant to seek medical assistance for problems as diverse as depression, stressful life events and symptoms of life threatening conditions like myocardial infarctions and cancer (Weissman and Klerman 1977; Padesky and Hammen 1981; Wyke et al 1998; White and Johnson 2000; Chapple et al 2004; Galdas et al 2005). In Western culture the ideal 'real' man is often portrayed as being a tough, unemotional, physically competent, competitive and aggressive (Lee and Owens 2002). Marginalised masculinities- deviations from this culturally exalted representation of being a 'real' man – are signified as being weak and inadequate (Phillips 2005).

Masculinity is a relational, evolving collection of meanings created in culture, constructed in relationships with others, meaning different things at different times to different people (Connell 1995; O'Brien et al 2005). In multicultural societies (such as the UK) there are likely to be multiple definitions, dynamics and norms of masculinity that are continually being constructed and reconstructed (Courtenay 2000). Having said this, this multiculturalism does not prevent the dominance of particular representations of masculinity historically epitomised as white, heterosexual, and middle class. Accordingly



in Western culture a white, heterosexual economically active male has been seen as 'normality' (Phillips 2005). While this might be viewed negatively and unrepresentative in other research contexts, in this particular study this hegemonic portrayal of men was strikingly accurate. All the men in the study were white, heterosexual and in varying degrees were or had been economically active. Whilst men are clearly not all the same and it does not make sense to assume that all men will behave in the same way in all help seeking contexts, the homogenous nature of the sample made it possible to draw commonalities between the men and these findings are discussed in the next few paragraphs.

The data clearly indicated that seeking medical help, or taking time off work, unless you were *seriously* ill was behaviour perceived by the majority of the men as acting 'soft'. Until they had confirmed that their symptoms represented a serious illness, or at the very least were not getting better, the majority had 'put up' with them. Hugh's account, starkly illustrates this theme.

Idah From your account it would seem that you were unsure about the mole so why didn't you get some help, like, you know, going to the doctor?

Hugh Well to be truthful I donno, I guess its like cultural, you know not wanting to be seen as soft and all. I think there is a lot of pressure, don't ask me from where, to go [to the doctor] only when you feel really ill, I mean I should really feel something was very wrong

Hugh was not the only one who felt that he should 'really feel something was very wrong' before seeking medical help. This sentiment was shared by others. Unfortunately the literature reveals a general tendency among the general public to give little attention to mole surveillance and other indications of MM because they are often not perceived as

significant or threatening (Montella et al 2003). As such, since most men did not feel threatened by their symptoms they did not feel the need to seek medical attention for them thus introducing delay.

Admitting to pain or any other problems was seen as a confession to being weak and threatened male pride and machismo. So entrenched was this belief that even when individuals recognised they needed to see a doctor they still perceived seeking help as a weakness. An example of this is Martin a 47 year old man who had a 7.8mm thick MM on diagnosis. Despite an increasingly growing and ulcerating lesion he perceived seeking health care for 'something trivial' as a weakness. This prevented him from going to see the doctor until he had to go for a two year health check up arranged by his employers.

Martin            You know at work, we have to erm, well they make us have these checkups every couple of years, so while I was there I said to the doctor, 'hey doc, check this out' and she was all like 'we need to get that seen to asap' . I mean, I was happy, could have gone on longer really but she was the doctor so I thought I had better listen (laughs)

Not being responsible for the instigation of the help seeking process seemed very important to Martin. The ability to say, 'they made me do it' seemed to remove the stigma of having initiated medical intervention and therefore not demonstrated weakness.

A central tenet of hegemonic masculinity in Western societies is the assumption that a 'real' man will have a full-time permanent job which supports his family financially - a 'breadwinner' identity (Price et al 1998; Connell 2000). Tolson (1977 pp 12 -13) noted that 'in Western, industrialised, capitalist societies, definitions of masculinity are bound up with definitions of work. Whether it is in terms of physical strength or mechanical

expertise, or in terms of ambition and competitiveness, the qualities needed to be a successful worker are closely related to those of the successful man'. During the interviews it emerged that several participants with professional occupations (mainly from higher socio-economic groups) had been reluctant to take time off work to seek medical help because they thought it would damage their work-place reputation of being reliable and dedicated. One participant was unequivocal in his view that taking sick leave would jeopardise his promotion opportunities. The following excerpts from Andy a 54 year old professional and Charles a 68 year old retired professional illustrate this:

Andy I didn't get this far by taking time off. I was always the first one in and the last one out. Its important to show that you're up for the job, you know, show everyone that you're like indispensable, always trying to impress people, trying to impress your bosses that you're worthy the promotion you've been after. That sort of thing. That's what it's all about. A lot of senior management, even today, yeah even me, would turn round and say 'well, there's two people up for this particular job, there's Tom over there with cancer and there's Dick who never has a day off sick', who do you think would get the job?

Charles When I was working, I never ever took time off sick. You just could not afford to be off sick, I did not want that label attached to my name, didn't want people thinking I wasn't reliable or anything like that

So concerned were these men about the image they were projecting to others that Andy admitted that even though he was entitled to sick leave with pay he did not tell his employers about his MM and took the time he needed to go into hospital for a wider excision as holiday entitlement.

Several men from lower socio-economic groups (those with a manual or unskilled occupation) and those who were self employed recalled their concerns about the financial implications of taking time off work. In addition to not wanting to appear 'soft', it was

apparent that these men had also decided not to seek medical assistance promptly because seeking medical help would have required taking time off work and losing money. The men had chosen to live with their symptoms and continued to work due to financial pressure. For example, Barry a 42 year old semi-skilled worker recalled that he had thought his mole was probably a tumour of some sort but despite its continued growth and darkening colour had not taken time off to visit the doctor but instead had continued to go to work because he needed to make money to live.

Idah Why did you not go to the doctor's then?

Barry Well yeah, to be truthful, I cant afford to take time off work to see the doctor unless its really serious

Idah Why?

Barry Because I don't earn that much and I only get paid for what I work, I need the money, you know, need to live, so you work extra shifts, long shifts, that sort of thing, you know what I mean?

Frank who was self employed also had concerns about taking time off work in order to visit the doctor. He had recently started his own business and had this to say

Frank Being self employed and all, its been quite tough. When I worked for a firm I had sick pay so I could take time off but now I just can't afford it, erm, I just can't afford to take time off work.....coz if I'm off work no money comes in and my family would suffer

There is little doubt that traditional helping services are underutilised by men and according to Addis and Mahalik (2003) it is likely that various masculinity ideologies, norms and gender roles play a part in discouraging men from seeking help. Men who held self-reliance, toughness, and pain endurance as part of their masculine identities resisted seeking help for as long as they could. From his work with men (Meek 2007) suggests that

most men had been *wanting* to seek help for a long period of time and denied it to themselves because of some combination of the aforementioned factors. However, they eventually got to a point where they simply could no longer avoid seeking help, getting them to a point of needing help. He goes on to hypothesise that men who allow themselves to seek help when they *want* it rather than when they *need* it demonstrate that they are secure enough with themselves to take action even when it goes against the grain of popular culture. This means that for many men, seeking-help can actually be a demonstration of strength, competence, and individuality. This alternative view of toughness and security can become the backdrop for a more evolved and sophisticated masculinity and will be discussed later in the thesis.

### 7.1.3 IS NOT COMFORTABLE VISITING THE DOCTOR

Another category to emerge from the data related to participants' attitudes to general practitioner attendance. This category identified further properties that impinged on the participants' decision to seek medical help for their symptoms. Many of those interviewed expressed a reluctance to visit their GP when they felt unwell. A number of reasons for this reluctance were forthcoming. To begin with, it would appear that seeking help is closely related to previous learnt behaviours. For instance, not being brought up to visit the doctor with small medical problems was a common theme. A minority of the participants were from a generation who were born before the start of the National Health Service so it may be quite possible that attitudes about visiting the doctor were formed in childhood when one had to pay for individual visits. There may also have been a combination of what may be long held attitudes about the reluctance of older people to complain of ill-health (Sidell 1995, Wright and Bramwell 2001). Ken a 73 year old retired

man who had finally visited the GP because his wife had insisted that he get the mole sorted out before they went on a three month cruise as she did not want anything to spoil their time away explained his reluctance to visit the doctor

Ken Me ma'am had six, there were six of us kids. And we were brought up when we were youngsters, 'Oh don't be silly you'll be all right'. Yeah we learnt to be tough, we never visited the doctor

Like Ken, many patients especially men perceived going to the doctor as a sign of weakness (see previous section 6.1.4) or not being tough enough. Not visiting the doctor was for them a source of pride (Galdas et al 2005).

Len I don't want you to think I'm always calling on the doctor, cause I don't call on them that much

Dave I've never been one to go marching off to see them [doctors] every time I've a funny throat or cough. It gotta be serious. I'm not one to waste resources

Other data from the study revealed that there was a degree of uncertainty in patients about when it was justified or appropriate to request an appointment with the doctor. There was almost a sense that visiting the doctor was an activity that should be rationed. There is evidence in the literature that the accounts of individuals who delay in consulting a GP often reflect inhibitions about 'bothering' the doctor with something that might prove to be trivial (Burgess et al 2001). From listening to the participants it was as though some believed that every individual has a certain amount of time credited to them by their GPs, and that this time should not be squandered by making visits for trivial matters, because when we really need it, it may all be used up. These individuals also believed that their GPs shared this perception with them. Bloor and Horobin (1975) discussed aspects of this 'triviality' in an early paper critiquing Parsons' (1951) functionalist analysis of both the

sick role and the doctors' role. They focused on what constituted appropriate grounds to see a GP, and the possibility of conflict arising between doctor and patient arising from this. During the 1970s, and indeed more recently (Tomlin et al 1999), British GPs were raising concerns about the proportion of 'trivial' conditions presented to them during surgeries. Their complaints centred around the number of unnecessary late calls and night visits, a general lack of intelligent use of the GP service by patients and the hundreds of 'neurotics who take advantage of free treatment' (Bloor and Horobin 1975 p.276; Tomlin 1999).

Bloor and Horobin (1975) propose that in a functionalist approach doctors would typify their ideal patient, as one who is able to assess their symptoms with sufficient expertise as to which conditions should be presented to the GP, but at the same time having assessed their condition, will then defer to the doctor's assessment on presentation. This, they suggest, has the potential to cause conflict between the doctor and the patient because in encouraging self-assessment by patients, they might arrive at a conclusion that is different from the doctors. Secondly, the approach may be counter productive because by asking patients to accept that the only person capable of assessing them clinically is the doctor, this might actually encourage them to take all their symptoms, however trivial to the GPs surgery. Although none of the individuals interviewed described conflict with their GPs, and most talked of having a 'good' relationship with them, there did however seem to be the perception that this 'good' relationship with their GP depended on them not abusing it by demanding too much.

An example of this perception was Winnie. Winnie, the oldest participant in the study, had just turned 83 at the time of the interview. Although pleasant and happy to talk, she was clearly uncomfortable because her feet were swollen and she needed assistance to elevate them. I asked whether she had called her GP. She quickly replied that she had not done so because she had already called him out twice in the last month about other medical problems and she could not call him out again because ‘I’m not the only patient he has, other people also need his help’. She expressed regret about not being able to go to the medical centre herself and seemed to accept her situation. Her neighbour and friend who came in daily to assist her had advised her to elevate her feet and that was what she was doing. Unable to determine the cause of the swelling, I did not feel comfortable to leave the situation as it was. I was therefore relieved when she informed me that the district nurses were due later that day and she said she would seek their advice. In their literature review of delay in detecting cancer symptoms, Antonovsky and Hartman (1974) suggest that at the very least, a comfortable relationship between the patient and their doctor is necessary because it removes barriers and reduces delay since discomfort in the doctor-patient relationship was mentioned in several articles they reviewed as a cause for delay.

An important element of the concept ‘Is not comfortable visiting the doctor’ was the finding that the way individuals reacted to their MM symptoms was not unique to the MM. It would appear that the delay or resistance to seeking diagnosis and treatment for observed MM symptoms was indicative of past help seeking behaviours. This supports the findings of other cancer research, particularly in breast cancer, that patients behave towards cancer symptoms as they do towards other life situations (Goldsen et al 1957;



Hackett et al 1973; Lauver and Ho1993; Facione and Dodd 1995; Caplan et al 1996; Bish et al 2005, Corner et al 2006). Delay, it seems, is not merely a response to the emergence of a specific symptom and its possible implications but more related to the ‘cluster of long-standing orientation to sociomedical problems that patients have built over a lifetime’ (Goldsen et al 1957 p. 2). During the interviews, one ‘delayer’ after the other used words like ‘never, seldom, rarely’ and phrases like ‘only when I’m at deaths door’ and ‘only when I am forced [usually by family]’ to describe their general help seeking behaviour. Formal health care- visits to the GP, hospital and the like was not part of their day to day reality and therefore seemed to play little part in their lives. They were not in regular contact with their doctor and therefore attempted to keep control over the events in their lives and care for their own health through a variety of measures such as self medication with ‘over the counter’ creams and emollients or by ascribing any new symptoms to other common or ‘normal’ events such as ageing. This process of ascribing new symptoms to common or normal events has already been discussed at length in the previous chapter of this thesis (see chapter 6 section 6.4.1).

Participants who could be described as ‘chronic delayers’ at the onset of any symptom were distinguished from those in the small theoretical sample who were usually prompt seekers of diagnosis for any symptoms. The four women in the theoretical sample of non-delayers all appeared more confident about sharing their concern with their GPs and did not seem to hesitate to seek medical intervention when they felt they needed it.

Lulu When I noticed it [a reddish boarder around an existing mole] I immediately rang my GP and made an appointment for the next day

Amy Well I knew it wasn't right the minute she [a fellow worker in the changing room] pointed it out to me and knew I best get it sorted out. I mean I don't erm really like going to see the GP but if you have something the matter then you have to go don't you?

They seemed to hold more consumerist attitudes to medical care and believed that the GP was there for their benefit. As such they did not seem to carry any feelings of guilt or uncertainty about visiting the doctor with their MM symptoms unlike the majority of the sample who stated that they would not visit their GPs with symptoms they perceived to be insignificant. When symptoms were finally mentioned to the GP, they were often brought up in passing, rather than in making a special visit to discuss new symptoms. Typically this was when the person had arranged a consultation for another health problem like a blood pressure check. In this way they had a legitimate reason for visiting the GP without making a special visit with symptoms that they were not sure whether the GP would view as legitimate.

#### 7.1.4 PREVIOUS BENIGN DIAGNOSIS

Much of the delay in this study was caused by the patient themselves for the reasons outlined above. In some cases, however, delay was further compounded by the doctor. An example of this was Simon. Simon a 58 year old professional had delayed in seeking treatment and diagnosis for a 'mark' under his foot because he did not perceive his symptom as a symptom of cancer. He knew quite a lot about skin cancer but because the 'mark' under his foot did not match his perceptions of what he thought skin cancer to be, he had delayed in seeking treatment until the lesion began to bleed. When he finally did go to the doctor her intervention further delayed his journey.

Simon In November last year getting up one morning I walked across the bathroom floor and notice that I was leaving a little trail of blood every time I put my foot down. We talk about cancer being, everybody knows a bit about cancer now and I knew that if you had anything moles, whatever and there is a change you need to get them looked at so that morning I was in the GPs surgery and erm she looked at it, gave me some antibiotic cream and said come back in two weeks. Now I said to her I think this could be skin cancer. In two weeks I went back and nothing had changed.

Idah Was it still bleeding?

Simon No, it wasn't.

Idah But it hadn't disappeared.

Simon No it was still exactly the same and she said well we better, we better have it looked at. So I came down here saw Dr X [the dermatologist].

His story was not uncommon, and other patients were also offered treatments such as steroid creams or a course of antibiotics to alleviate their symptoms. Doctors also often reassured patients that they had nothing to be worry about and to return if they were still concerned at a later date. After these initial interventions failed to have the desired effect and the patient returned, usually within a month, most doctors reacted quickly and referred the patient to specialist care. Unfortunately, a minority of patients had not immediately returned to the doctor after the initial consultation. A major reason for this appears to be related to their perception of the doctor. These participants had trusted the doctors' judgement, often because they had a long term relationship with them or simply because they were a doctor and as the 'expert' the patient assumed they could be trusted to make the right decision. When doctors did not appear to be concerned or alarmed patients were reassured and accepted their reassurance. Dave a 68 year old man recounted how he had decided not to have his mole excised because his GP had not seemed concerned about it.

Dave But she wasn't alarmed with the mole or anything like that and she didn't think it was anything urgent and she said we will leave it up to you, that's the procedure

that we would do and its up to you whether you have it done or not. So I didn't get it done

He only returned to the doctor 16 months after the initial consultation when the mole started bleeding.

Like Dave, most of the other patients who had not promptly returned for further consultation took their cues from the doctor. Where doctors appeared confident and self-assured patients often trusted them, sometimes even against their own better judgement. The most striking example of this was Jane, a health worker with over 20 years of experience who despite believing her moles were malignant did not seek a second opinion after her initial consultation with her GP (who had a special interest in dermatology) because she felt 'foolish' after he had assured her that in his 'expert opinion' she had nothing to worry about.

Jane It was a mole. It was actually two moles. New moles. And eventually they sort of joined up together and changed shape. And I became concerned about them so I went to the GP who told me I was fussing unnecessary. But I said to him I thought they were malignant. But he wouldn't have it. And then, he made me feel such a fool I did, I did nothing about it for about a year after that.

In recent years there appears to have been an erosion of trust in the relationship between doctors and patients (Chin 2001; Maynard and Bloor 2003), possibly exacerbated by highly publicised incidents of wrong doing by doctors like serial killer Harold Shipman but also because patients have a greater awareness of their rights and more access to information, principally through the internet. Despite this 'erosion of trust' pollsters commissioned by the Royal College of Physicians found that members of the public still trust doctors above all other professionals (Royal College of Physicians 2008), which

would explain the findings from this study. Added to this, results obtained from a standardised questionnaire administered to 429 patients in Blum et al's (1999) study, revealed that among the factors associated with delay in diagnosing MM, an initial incorrect diagnosis as a benign lesion by the doctor first visited had the highest significance. These results exemplify how trusting the doctor's judgement can sometimes lead to further pre-diagnostic delay.

The manner in which symptoms were communicated to the doctor also seems to have contributed to participants being given a benign diagnosis. Most admitted that they had mentioned the symptoms in passing when they had visited the doctor for another, (more pertinent) reason as illustrated by the following excerpt from an interview with Nancy.

Nancy To be truthful, its alright to be all righteous indignation now but to be fair to him I think the way, it's the way I told him about the mole. I was more concerned about the stomach cramps [the original reason she had gone to see the doctor] and at the door, it was only when had given me the prescription and I was at the door when I remembered and kinda mentioned it. He came to the door and sort of peered at it, but it was kinda awkward considering that I had one hand on the door and the other outstretched for his inspection

Research has shown that even experienced doctors are influenced by the salience of particular symptoms over others when making diagnoses (Garb 1996). Just as patients take their cues from the doctor, doctors also take their cues from patients. Leydon et al's (2003) small scale study that provides insights on the journey towards a cancer diagnosis found that how patients communicated their symptoms determined how seriously they were taken. As discussed in the previous chapter (see section 6.3.1) for many participants knowing what was 'normal' and knowing what was reasonable or bad enough to warrant making an appointment was an issue and they worried that they might be wasting the

doctor's time and be criticised for it. As such few made a special appointment to see the doctor about their MM symptoms and tended to seize the opportunity to mention them when they were visiting for something more 'legitimate'. They were also cautious about how they told the doctor about their symptoms often choosing a more casual flippant approach over a serious one.

## 7.2 FAMILY, FRIENDS AND SIGNIFICANT OTHERS

Throughout the discussion of the research findings glimpses of the role played by family, friends and significant others in the participants' pre-diagnostic journey have been given; for example Colin's mother making an appointment for him to see a doctor about the mole on his back (section 6.2.3) or June failing to make an appointment to see the doctor about her MM symptoms because caring for her autistic son seemed more important at the time (section 7.1.1). What these stories and others illustrate is that other people influenced all participants at some stage of the decision-making process giving further credence to Lee and Newby (1983) assertion that it is not possible to have a totally isolated, non-social individual. Contrary to the researcher's initial simplistic expectations that family and friends would be instrumental in helping the patient to seek care, the role played by these individuals was not always as clear cut and they sometimes turned out to be a major contributory factor in patient delay. The role played by these significant individuals in the participant's decision to seek medical help will now be discussed.

The most notable role played by family and friends was in encouraging the participant to seek medical attention. Most participants had discussed their symptoms with another

person usually a partner but also with friends, and for some, with their children prior to discussion. In the main these discussions had focused on the nature of the symptoms and whether they were serious enough to warrant seeking medical intervention or not. This finding has been reported in numerous other studies of delay across a wide range of cancers and sharing one's experience with others appears to be a common feature of patient experiences. It appears that it is important for patients to receive validation for their concerns and reassurance that their symptoms warrant help seeking and that they are not 'blowing things out of proportion' (Facione 1993; Gascoigne et al 1999, Burgess et al 2001; Leydon et al 2003, Chapple et al 2004). However, what was particularly interesting about the findings from this study is that patients were not the ones who often sought validation from their families and friends. Rather, it was the family and friends who often seemed to be convincing the patient that their symptoms warranted medical attention. Since the findings in chapter six suggest that patients often did not perceive themselves to be at risk of MM and perceived their symptoms as non-threatening, it was often left to family and friends, who often perceived the danger before the patient, to persuade, convince, plead, bully, cajole and pressure them into seeking help.

Only four 'delayers' and three 'non delayers' recounted seeking validation from family and friends. Among those who delayed Jane, a health worker had sought validation for her concerns from her colleagues. Samantha had sought validation from the internet and Len and Dave from their wives. All three of the 'non delayers' Lulu, Bev and Chris sought validation from their respective spouses. All the other participants had to be convinced that they needed medical attention and often argued with those advising them as such.

Even among those classed as 'non delayers' Colin and Andy had not sought medical attention of their own volition but were prompted one by his mother and the other his wife who coincidentally were both nurses.

Several participants talked about a tension between their desire to maintain their independence and others' concerns for their welfare. This tension manifested in many ways. A couple of participants described particularly tense situations. George and his wife, who was present during the interview, described the tension created by George's refusal to go and see the GP about a mole on his shoulder.

George's wife            Well I knew it certainly wasn't right but try telling him that

George                    She kept on at me, on and on! She knows I am independent so I said 'no I'm not going' and she said 'yes you are'. Don't be deceived by the height she can be one tough cookie (both laugh)

George's wife            As I said I knew it wasn't right, and we kept arguing about it, tell you something, he can be so stubborn

Idah                        So what finally happened?

George and his wife simultaneously    It was either the mole or her! (laughs)  
I threatened to divorce him!(laughs)

Others had this to say about their families.

Sue                        they're pressuring me going to see my GP [her children]

Andy                      you have never seen anything like it, go and see the doctors nag nag nag [his wife]

Ian                        she wouldn't let up, literally forced me [his mother]

Winnie                    I got tired of him pestering me [her son]



In spite of the family and friends' intentions, participants did not always take the advice they were given or believe it, sometimes to their detriment. For example, for nearly two years Bob's wife and daughter had unsuccessfully tried to convince him to seek medical help for a 'mole' on his arm. His refusal to take their advice meant he presented late and later died of his disease. Paul had ended up with what he described as a large unsightly 'hole' on his face because a year earlier he had not believed his friend who had told him the mole on his forehead looked 'suspicious'. In two cases participants were prompted to seek care because of cancer experiences within their families.

Idah            So you say you had seen the information at the doctors surgery, was there anything else that influenced your decision in going to see the doctor, apart from the posters that you had seen.

Samantha    My father died of cancer and my mum mother died she had a brain tumour, my aunt had cancer, she also had it removed from her throat and there is quite this history in my family and I have always joked I will die of cancer whatever at the time I just thought I was about something or nothing, I didn't think there was something wrong with me then I just thought in the back of my mind I should get it checked out because from the age of 15 to about 30 I used to go on the sun beds quite a lot and there was also a big thing about sun beds and I just thought since there was so much of it in my family anyway, so even if they are dead I guess my family made me go

Idah    So you wouldn't have gone with your mole, not even the bit of pain?

Barry    No. The reason I went to the doctor a couple of years ago with the mole, my mother died and when I was with my brother, my brother noticed the mole and my mother died of breast cancer and my brother said please go to the doctor and get that mole removed. And I suppose at that particular time my emotions were high and so I did, I rang the doctors and that is why I went to the doctor to ask about the mole.

In the literature there seems to be a mixed response to seeking medical attention for possible cancer symptoms because of a family history of cancer. In some studies (especially related to breast cancer), patients with a family history of cancer were less

likely to delay in seeking medical care (Harirchi et al 2005). This might be because an enhanced perception of their own risk led them to take more immediate actions upon discovery of symptoms. In addition, they might have observed the full range of treatment modalities offered to their relative, removing some of the fear often associated with a cancer diagnosis and treatment options (Harirchi et al 2005). In others studies a family history of cancer was cited as a reason for delay (Manly-Lampkin 2003). Although fear of experiencing what a loved one experienced, particularly if their experience was negative, is cited in the literature as a reason for delay (Manly-Lampkin 2003), in this study there was no evidence that the participants were fearful. Rather, it appears that their loved ones experiences invoked an emotional response from them and it was almost as if they were 'honouring their memory' by going to seek medical help for their own symptoms.

For others a perceived desire to protect their family members precluded them seeking help for themselves, especially when they felt that revealing their symptoms would put 'unnecessary' pressure on their loved ones. For example Julie (section 7. 1.1) desire to protect her partner arose from the fact that he had just been diagnosed with diabetes himself and she did not want him to have to worry about her too. In another example, Clive had been diagnosed and treated for colorectal cancer in the past. Reflecting on the experience, he recalled how traumatised his wife had been by the experience and decided to 'protect' her from the possibility of another cancer diagnosis. Even after the lesion on his shoulder blade became painful and a friend advised him to seek medical help he could not find a suitable 'excuse' to make an appointment with the doctor without worrying his

wife. He finally got an opportunity when his wife went away to visit family for a couple of weeks.

Clive She worries and I didn't want the worry on her, you know, I felt right devious, as if I had a dirty little secret or something. When she came back I had to tell her and she says 'why didn't you tell me?' and even then I'm like 'oh I'm sure its nothing' but I could see she was already beginning to worry

Whilst the family members can not be blamed for directly causing the participants to delay in presenting their symptoms for medical help, it was the altruism participants felt towards them that contributed to their delay.

Delaying help seeking as a consequence of perceived role demands and responsibilities for the health and domestic needs of other family members was another way family and friends indirectly contributed to the patient delay. Several examples of participants prioritising their social role demands and responsibilities before their own health have been given in this chapter. From Peter looking after his poorly wife (section 7.1.1) to Frank failing to take time off work because of the financial implications for his family (section 7.1.2) putting the welfare of others before their own meant that their own health needs were not always prioritised and these participants delayed in seeking care.

### 7.3 STARTING THE BALL ROLLING (triggers for action)

Commenting on the studies of delay in cancer Zola (1973) makes the interesting observation that despite the initial delay 'there is a curious methodological fact about these studies for all these investigations were done on *patients*, people who **had** ultimately decided to go to a physician. What happened?' Clearly *something* has to happen to turn the individual from delaying to seeking help, from a person into a patient (Zola 1973).

Being able to participate in the study is evidence that all the participants eventually sought medical assistance for their symptoms. In most cases it is possible to establish ‘what happened’ and ascertain the influences that provoked help seeking.

The most common trigger for action identified in the study was when the participant had to visit the doctor for something else and used the opportunity to mention their MM symptoms whilst they were there. Since the participants had waited until they needed to see the doctor for another ailment or reason this implies that even though they had noticed their MM symptoms there were still barriers that prevented them from seeking help immediately. Most admitted that they would not go to the GP with their MM symptoms alone. The main reason identified for this was because they did not perceive them as being serious enough to warrant seeking medical attention. The emergence of more salient symptoms or what they perceived as more legitimate reasons for going to see the doctor such as vaccinations for holidays or routine checkups for chronic conditions like hypertension gave the participants a valid ‘excuse’ to seek help for their MM symptoms without worrying that they would be accused for wasting the doctor’s time or being over anxious.

The second trigger for action identified from the study was pressure from family and friends. Zola (1973) refers to it sanctioning. As discussed in the last section (see section 7.2) family and friends were often responsible for pressuring the participant into seeking medical assistance. For those who sought validation it would seem that the decision to

seek medical help was hastened when those that the patient chose to confide in explored and validated their concerns.

Bev Well he [her husband] looked, well examined it quite thoroughly and then suggested we do a little search on the internet. He is very good at that sort of thing... so yes, at least he took me seriously

From their internet search, Bev (one of the non-delayers in the study) and her husband were forced to consider that her lesion might be a form of skin cancer which precipitated her help seeking behaviour. On the other hand when the participants failed to get validation for their symptoms this often led to further delay. For instance, Kate and Joan both consulted their husbands who reassured them their symptoms were 'nothing' and therefore they had no reason to be concerned. Both trusted their husbands' judgement and became complacent, doing nothing more about their symptoms until (coincidentally), both husbands changed their minds. Kate's husband had become concerned that her lesion seemed to be a little inflamed while Joan's husband, still not convinced that it was anything serious but a bit concerned that it was not going away, had advised her to go and see a doctor 'just in case'.

Early MM symptoms are usually not severe and as such are often dismissed as trivial and insignificant. If left untreated for extended periods of time, however, they worsen, become more noticeable and harder to ignore. This was the third reason for seeking action identified by the study. Although most of the participants had initially delayed in seeking medical assistance, as their symptoms progressed they became increasingly concerned. The most common physiological changes reported were bleeding, ulceration, pain, skin breakdown, inflammation and itching. These findings are supported by much of the

literature around presentation delay in MM that suggests that individuals are more likely to respond to late features in the progression of MM like the ones described by the participants in this study (Blum et al 1999; Richard et al 2000; Montella et al 2002; Negin et al 2003). In addition to the symptoms described above, individuals often seemed to intuitively know that something was amiss. Interestingly, twenty of the forty two interviewees used the words ‘not right’ to describe their lesions. Reasons given for this were lesions not going away, becoming a strange shape, dramatically changing colour (often becoming much darker), and lesions that had grown bigger and/or rough to touch.

Zola (1973) uses the phrase ‘temporalising of symptomatology’ to describe the final trigger for action identified in the study. The ‘temporalising of symptomatology’ is an external criteria for action- such as ‘if it isn’t better in 3 days, or 1 week, or 7 hours, or 6 months, then I will take care of it’ used by the participants before seeking medical help. Some of them spent time monitoring their symptoms and re-interpreting what they were experiencing, before negotiating with themselves or others as to when services needed to be accessed. For instance, both Andrew a 50 year old man and his partner could not decide whether a ‘purple bruise’ they believed he had received when he hit the car door against his leg needed medical attention or not.

Andrew’s partner      It sort of became a running theme to look at it before we went to bed, every night before going to bed, we would look at you know kinda observe it to decide if it was worse or better. Little bugger couldn’t make up its mind, one minute it was just about *normal* the next it was all angry again!

After a few weeks where it seemed to subside and then resurface again they agreed to observe it for a week and if it had not completely disappeared by then they decided

Andrew would go and seek medical advice. This seemed to be a particularly agreeable arrangement because Andrew was self employed and had no jobs planned for the following week.

The example of Andrew and his partner discussed above illustrates another important finding from the study- ‘triggers for action’ seldom happened in isolation. Although described individually, it was not unusual for several factors to come together to ‘start the ball rolling’. Andrew was self employed and one of the people who had expressed concern about the financial implications of taking time off work to see a doctor. Temporalising his symptoms combined with the fact that he had no work the following week meant the time was right to seek for medical help. Other examples of the ‘time being right’ and factors coming together to facilitate help seeking behaviour include Martin (section 7.1.2) and Matthew (section 6.3.2). Martin considered it a sign of weakness to seek medical help for symptoms he considered as trivial. After putting off the decision to see a doctor for several months, he admitted that he was becoming increasingly concerned because his ‘mole’ had become ulcerated and did not seem to be healing. A health check-up provided by his employers every two years gave him the opportunity to visit the doctor without admitting to any ‘weakness’ and since he could no longer simply dismiss or ignore his symptoms he mentioned them to the doctor which started ‘the ball rolling’. On the other hand Matthew initially reacted to his mole by doing nothing until it started bleeding and leaving blood stains on the sheets and his shirts. At this point, because of the bleeding he could no longer ignore his lesion and the bleeding alarmed his wife who began to put pressure on him to see the doctor making it the right time for him to seek medical treatment. Once the triggers

for action had been set in motion, patients sought help for their symptoms and curative treatment began.



PART FOUR

**DISCUSSIONS AND RECOMMENDATIONS FOR  
PRACTICE**

## 8. CHAPTER EIGHT

### PORTRAIT OF A DELAYER

#### 8.1 INTRODUCTION

The study presented in this thesis aimed to explore the following question, borne out of observations in clinical practice and gaps identified in the existing body of empirical evidence, as outlined in the introduction of this thesis:

**‘what are the challenges, if any, that individuals subsequently diagnosed with malignant melanoma face that impede or facilitate their presentation for diagnosis and treatment?’**

In other words, what makes a delayer? The main focus of this thesis has been to understand presentation delay in MM for as Andersen et al (1995) point out, patient delay in seeking a cancer diagnosis is an important problem. Not only does early detection increase the survival rates for those affected but ‘catching’ cancer early in its trajectory improves the quality of life following treatment. One of the key features of GT analysis is to try and form a core concept or explanatory theory to account for all the varied evidence in the data in order to give a complete picture of the phenomenon under study. Re-reading the interviews, questioning the data and writing a narrative of the story line (presented below) helped to produce the core processes of the study which relate to how individuals *perceive* their situation or circumstances. This ‘perception’ relates to a psychosocial process by which participants assessed their physiological and non physiological circumstances and gave meaning to their experiences. The central tenet is the *perception*

element of the process and how this was interpreted by participants themselves to influence their actions.

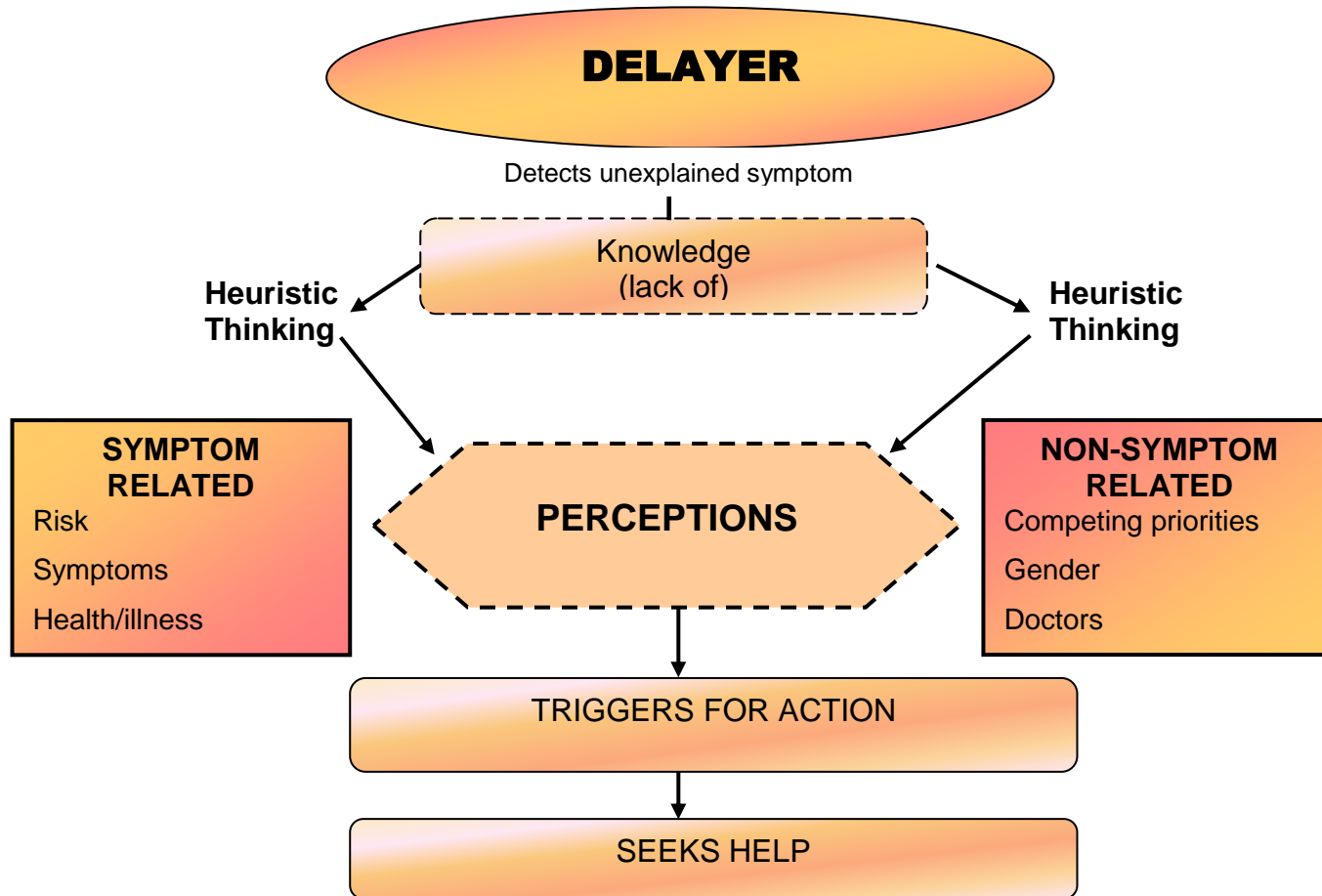
The study of perception is the study of how meaning is brought to the information received by the senses (Bernstein et al 1991; Adams and Bromley 1998). It is about the way individuals make sense of their world, both external and internal. A person's senses are continuously receiving data about them and the environment and sending signals in the form of 'action potentials' (Adams and Bromley 1998 p 208) to the brain. Most of this incoming information is monitored unconsciously so that much of their behaviour and physiological processes are usually automatic. However, sometimes an individual pays conscious attention to some of this data and can talk about what they identify, and make conscious decisions about what they do (Bernstein et al 1991; Adams and Bromley 1998). It is often said that we see what we want to see or what we expect to see, illustrating that the process of perceiving is not just a passive 'picking up' of sensory messages but also often involves filling in some gaps and hypothesising from incomplete data (Bernstein et al 1991; Adams and Bromley 1998; Alder 1999; Ogden 2007). Understanding the process of perception helps in appreciating the similarities and differences between people. How an individual interprets their circumstances is unique, depending on their past experiences, personality and knowledge. In this study, it was particularly important to be sensitive to how individuals perceived their symptoms in order to understand why they had delayed in presenting for diagnosis and treatment.

This core process facilitates the creation of a ‘portrait of a delayer’- a portrayal or depiction of individuals who delayed in presenting their MM symptoms. This ‘portrait of a delayer’, depicted diagrammatically in figure 8.1, is generated from the evidence of the participants (presented as the findings in the previous three chapters of this thesis) and is an amalgamation of these findings and the literature examined in the first three chapters of the thesis especially the Model of Patient Delay presented in figure 2.2. In the true spirit of constructivist grounded theory which emphasises *understanding* over explanation (Charmaz 2006) this chapter links the various components that have emerged and developed from the study and utilises them to provide an avenue for understanding presentation delay in MM.

## 8.2 THE PORTRAIT OF A DELAYER

The Model of Patient Delay (see section 2.3.3) describes the separate stages of patient delay which are passed through successively, each move being attended by a balanced decision. According to Andersen and her colleagues (1995) these delay intervals do not correlate and are therefore independent. Although findings from this study suggest that in practice the stages do sometimes overlap, the general process of patient delay described by this model found resonance in the present study. In many ways the model outlines the ideal MM presentation journey. In this journey the patient detects unexplained signs and symptoms, assesses them and infers illness, decides to seek medical attention, acts on the decision by making an appointment, is given an appointment and enters formal medical care. As such, the various stages of the model have formed a useful framework to structure the models described in this study.

Figure 8.1 Portrait of a Delayer



The Symptom Interpretation diagram (see Figure 6.1 p. 175) is a break down of what occurs during ‘appraisal delay’ and the Social Aspects of Delay diagram (see Figure 7.1 p. 216) describes various elements of ‘behavioural delay’ in MM patients. The ‘Portrait of a Delayer’ (see Figure 8.1 p. 252) is an amalgamation of these two models and further illustrates how closely they are related to Andersen et al’s Model of Patient delay (1995), bringing into sharper focus other elements like the role played by knowledge, heuristic thinking and the patient’s perceptions in the process of delay. Since the ‘Portrait of a Delayer’ diagrammatically illustrates the core processes that occur in MM patient delay, the next few paragraphs will concentrate on identifying how it is related to the Model of Patient Delay outlining similarities and pointing out developments. This will enable the author to effectively demonstrate the contribution the new model makes to current knowledge.

Petrie and Weinman (2003) describe the model of delay as a road map in that it tells what towns one will go through, but the map of the actual towns themselves is lacking. Very little is still known about how delay occurs at each stage- particularly the stage where individuals decide they are ill- and how people progress from one to another. Understanding this transitional period when individuals move from seeing themselves as well to seeking medical treatment for symptoms is crucial because it will help us to design better interventions to reduce delay. The Portrait of a Delayer in Figure 8.1 supports the Model of Delay in that it describes what happens to MM patients during the appraisal period and offers an explanation for their actions.

In common with many other illnesses, the bulk of the total delay period in MM appears to be accounted for by the first stage of symptom appraisal. It seems that most of the challenges faced by delayers are concentrated at the beginning of their journey (detecting symptoms and inferring illness). The Portrait of a Delayer breaks down this process and outlines the actual challenges faced by the MM patients in this study that caused their delay in seeking medical intervention for their symptoms. In line with the Model of Patient Delay (Andersen et al 1995) some of the challenges arose from how they interpreted (or in this case *misinterpreted*) their symptoms. Furthermore, the Portrait of a Delayer builds on from the Model of Patient Delay by recognising that delay is not exclusively caused by symptom interpretation issues but also by other social causes. For example, the social roles and responsibilities that individuals have may compete with their symptoms for priority.

In addition, from interviewing the patients it is clear that in their minds their presentation journeys were not divided into clear cut stages and intervals as the Model of Patient Delay would suggest. The time required to pass through the entire process differed from person to person. For some individuals the various stages overlapped and they progressed from one stage to the next fairly quickly. For others, the progression from stage to stage was slow and drawn out. Results from the interviews suggest that the decision to seek medical intervention is a highly individual one. Here too the Portrait of a Delayer complements the more generic Model of Patient delay by highlighting the crucial role played by individual thoughts and perceptions in the decision to seek medical help for symptoms.

### 8.3 THE STORYLINE

In many ways the process of delay can be likened to a race where the athlete has to successfully jump over several hurdles in order to reach the finishing line. Each hurdle represents a challenge that has to be overcome. Each hurdle has the potential to hold the athlete back. Likewise, the delayer is faced with many challenges. In order to arrive at the point where they seek medical help they need to successfully overcome each hurdle. Failure to overcome hurdles leads to delay. As illustrated by figure 8.1, after detecting an unexplained symptom the first hurdle that the delayer has to overcome is the knowledge barrier. De Nooijer et al (2001b) hypothesise that if someone has insufficient or incorrect knowledge, then it is impossible for them to interpret suspicious symptoms correctly. This hypothesis was supported by the evidence in the study (see section 6.1) and appears to be one of the major factors that contribute to presentation delay.

In the face of uncertainty research shows that human beings tend to turn to mental shortcuts known as heuristics to process information to make a decision. Although these heuristics or intuitions can be strategies for decision making, in the case of triggering help seeking for MM symptoms they are often ineffective because individuals have insufficient or incorrect knowledge to begin with. Studies of heuristic thinking demonstrate that, regardless of the hazard, human beings typically estimate their own risk and personal susceptibility as being less than others (Weinstein 1982; Slovic 1987). This is what seems to happen in the scenario presented by figure 8.1. Sometimes individuals have sufficient knowledge to recognise that they need to seek help for their symptoms but their social circumstances work against responding speedily. Whichever route they follow, or



whatever their reasons, the end result is the same- a failure to seek medical help thus lengthening the period of delay. But the story does not end here. Although delayers do not seek help for their symptoms it appears that they keep a watching brief on them. The intensity of surveillance varies as does the length of time until ‘something’ happens to trigger them into action. These triggers for action (discussed in chapter 7) include sanctioning or validation from people around the individual, symptoms that can no longer be ignored because the symptom status has changed (e.g. started bleeding), a chance to visit the doctor (usually with an unrelated problem), and temporalising of the symptoms. The delayer then seeks help and diagnosis and treatment usually ensues.

Having presented the storyline above, it is important to revisit the original key research question of this work in the context of the research findings presented in the storyline and weave the threads of this thesis together in order to bring the ‘portrait of a delayer’ to life and illustrate how presentation delay in MM can occur. As such, the next section of this chapter will seek to address the research question by discussing figure 8.1 in greater detail, outlining the challenges that individuals who delay in presenting for medical assistance face and the facilitators or triggers for action that allow them to finally overcome the barriers to seeking medical advice.

## 8.4 THE CHALLENGES

### INSUFFICIENT AND INCORRECT KNOWLEDGE

As Kahlil Gibran (1960) once said ‘A little knowledge that acts is worth infinitely more than much knowledge that is idle’ and idle knowledge was one of the challenges faced by

the delayer. Knowledge is recognised as a key component in decision theory. In the information processing model (Bransford 1979), knowledge is the ‘fuel’ stored in long-term memory and released by short term cues. On one side of the equation, it is clear that a lack of knowledge results in patients failing to appreciate the gravity of their symptoms and not seeking medical intervention (Rampen et al 1988; Blum et al 1999; Oliveria et al 1999; Schmid-Wendtner 2002), on the other side research such as this one and others (Sheikh and Ogden 1998; Knight et al 2002; Ma et al 2007) shows that knowledge alone is often not enough to prompt individuals to act.

If all the research participants were placed on a continuum from little to well informed in terms of MM knowledge, most would fall somewhere in the middle. As discussed in chapter 6, apart from Agnes and Winnie who claimed to have no prior knowledge of MM before their diagnosis, all the other 40 research participants knew something, in varying degrees of sophistication, about skin cancer and MM. In fact, during the course of the interviews most were able to describe the classical symptoms of MM such as a change in colour, increase in size and elevation of a pigmented lesion as possible signs of MM. Some also understood the association between sun exposure and MM. The information that formed the basis of their knowledge came from a wide variety of external sources like family, friends, the internet, magazine articles, professionals as very few of them had ever actually experienced MM first hand. Despite having this knowledge they still delayed in presenting for medical help. It would appear that the hurdle was not simply a lack of knowledge but involved a failure to translate knowledge into action- idle knowledge. There was among the participants almost a uniform inability to make the connection

between what they knew about MM and their individual symptoms. The consequence was that symptoms went untreated for longer. Ultimately knowledge is meaningful information, but meaning is not inherent in information; it requires interpretation to turn mere data into something that can be analysed and acted upon.

## HEURISTIC THINKING

As discussed above, in making any important decisions the decision maker needs to possess a degree of knowledge. Thus, in order for an individual to decide to seek medical assistance for symptoms of MM they need to possess some knowledge about the meaning of their symptoms (De Nooijer et al 2001b; Galotti 2002). Health education programmes assume that with some knowledge it is possible for an individual to attempt to estimate their personal risk of being diagnosed with MM by systematically considering the relevance of their symptoms against a number of variables associated with MM such as colour, asymmetry and elevation of lesions. However, research on human thinking suggests that such a systematic approach to personal risk estimation is highly unlikely. As Facione et al (2002) point out, unlike computers, human beings are incapable of accurately calculating the probability of personal risk and compensate by using mental shortcuts known as heuristics when processing information to make decisions.

The first thing that can be said about the commonly adopted heuristics that people use is that they have their place (Tversky and Kahneman 1974; Galotti 2002). Typically, they are ways of thinking that work well under many conditions but, as is the case with presentation delay, can also go drastically wrong. Von Winterfeldt and Edwards (1986)

defined these heuristics as ‘cognitive illusions’ – discrepancies between an objectively correct answer and people’s intuitions about the answer. These ‘cognitive illusions’, though often not discussed in the healthcare context, tell something about the ways in which people gather, sort and integrate the information that goes into making decisions. Some of the major heuristics; representativeness, availability and anchoring first identified in Tversky and Kahneman’s (1974) seminal work will now be discussed in relation to MM and how they often become another hurdle that the delayer has to overcome.

Tversky and Kahneman (1974) observed that as a part of the human need to create meaning from experiences, people tend to judge the probability of an event by finding a ‘comparable known’ event and assuming that the probabilities will be similar. They labelled this ‘rule of thumb’ as the representativeness heuristic. Garb (1996) suggests that representativeness can be thought of as the reflexive tendency to assess the similarity of outcomes, instances and categories on relatively salient and even superficial features, and then to use these assessments of similarity as a basis of judgment. People, it seems, assume that “like goes with like” and therefore things that go together should look as though they go together. The representativeness heuristic is possibly one of the main reasons why participants in the study attributed their symptoms to common ailments. Although patients observed the changes, in the face of insufficient and incorrect knowledge they judged their symptoms according to other ‘comparable known’ events. Since they did not encounter MM in their daily living they attributed their symptoms to more familiar ‘everyday’ occurrences such as congenital moles, marks, spots and

blemishes on the skin, freckles, acne, normal itching of the skin and normal changes that occur to the skin as a result of ageing.

Availability, the second rule of thumb identified by Tversky and Kahneman (1974), is a cognitive heuristic in which the decision maker relies upon knowledge that is readily available rather than examine other alternatives or procedures. In other words, people make judgments based on what comes to mind more easily, rather than complete data. This process has generally been demonstrated by asking participants to assess the relative likelihood of two categories in which instances of the first category are more difficult to recall than instances of the second category, despite the fact that instances of the first category are more common in the world. For instance, Slovic et al (1982) compared people's estimates of the frequency of death from various causes with the actual number of deaths attributed to each. Interestingly, they found that homicides were incorrectly judged as frequent as deaths from strokes although the reality was that strokes claimed about 11 times more lives at the time. This inaccuracy in judgment was probably caused by the fact that homicides are more vivid, receive more publicity and are easier to remember than strokes. In the present study, rather than think of alternative explanations for their symptoms, participants focused on what came to mind more easily, such as other moles they already had and assumed the MM was no different. This observation is in line with Andersen et al's (1995) assertion that individuals are more likely to consider their symptoms to be caused by normal life circumstances than by cancer, inadvertently leading to longer periods of delay.

The final heuristic identified by Tversky and Kahneman (1974) is the anchoring and adjustment heuristic. People who have to make judgements under conditions of uncertainty use this heuristic by starting with a certain reference point (anchor) and then adjust it to reach a final conclusion such as help seeking in MM. Anchoring can cause individuals to ‘under react’ to new information. For example, when an individual’s symptoms initially present as an innocuous lesion they are labeled as being insignificant and harmless and this label is ‘anchored’ in the individual’s mind. Thus even if ‘new information’ in the form of concerns expressed by others or changes in the symptom itself (such as pain were there was none) comes to light, the individual fails to act because their mind is firmly fixed on the original notion of the symptom as insignificant. Though defined separately these heuristics are instinctive and more often than not individuals might apply all of them simultaneously to make decisions without actually being conscious of it.

When faced with sorting out the morass of information that often accompanies the decision to seek medical help, patients must determine what information is the most salient to present to the doctor in order to receive an accurate diagnosis. Symptom salience, the subjective perception that one symptom is more important than others (Brannon and Carson 2003), is one factor that might influence the decision to seek care. Indeed, although it is often assumed that experience leads to greater accuracy in decision making, research has shown that even experienced doctors are influenced by the salience of particular symptoms over others when making diagnoses (Garb 1996). On the other hand, another factor that may also increase the delay in making the decision to seek

professional care is symptom ambiguity where symptoms are not particularly striking or where a multiple diagnosis or common explanation for the symptoms is possible. Such a scenario requires the patient to selectively pay attention to symptoms that they perceive as more deserving of medical attention. Symptom ambiguity results in medical diagnoses being a probabilistic activity even for experienced diagnosticians (Garb 1996) and as such it is not surprising that patients often get it wrong. Given the wide range of symptoms people are known to experience on a day to day basis and the seemingly endless potential diagnoses for any particular symptom, it would be inefficient for a potential patient to pursue each individual symptom in the process of making a decision to seek medical care. Instead, it is likely that individuals will use heuristics to aid them in their decision making process.

## 8.5 PERCEPTION

In psychology the term 'perception' is often defined as the interpreted message from the senses and is therefore linked with the term 'sensation'. In the English language however, the term 'perception' has wider connotations than anything that has to do with the senses and sense-organs and generally implies, if only in a metaphorical sense, a point of view. The Compact Oxford Thesaurus and Word Power Guide (2002) offers words like apprehension, cognition, discernment, perspective, recognition and understanding as alternatives for 'perception'. Constructionists like Irving Rock (1983) emphasise the knowledge based, inferential characteristics of perception and as demonstrated by Figure 8.1, in this study, knowledge and heuristic thinking played a major role in helping to shape the participant's perceptions. Once perceptions are formed it is difficult, although not

impossible, to reverse them (Bernstein et al 1991; Alder 1999). As such one of the greatest challenges faced by the participants in the study was to override the perceptions they had formed in order to recognise that they needed to seek professional care for their symptoms.

The findings from this research project identified two broad categories that accounted for presentation delay in this sample of MM patients. The first category (chapter six), deals with the perceptions involved in interpreting symptoms. These include how individuals judged their risk of getting MM, how they interpreted the symptoms themselves and how they understood illness and health. In many ways these perceptions were cognitions because they happened internally and although it can be argued that they helped individuals to make sense of their symptoms, this often lead to presentation delay because misinterpretations occurred. In addition to these symptom related perceptions, the second category identified other non physiological factors such as perceptions of life responsibilities and commitments, perceptions of masculinity and perceptions of medical services as also being factors in presentation delay. These factors, discussed in the seventh chapter of the thesis, can be described as social because they centred on the patient's relationships with other people.

#### **SYMPTOM RELATED PERCEPTIONS**

Results from the study reveal that the way people perceive their symptoms has a significant bearing on what action they decide to take. It can be argued that where symptoms are perceived as a significant threat individuals are more likely to be motivated



to seeking help for them. As discussed in the third chapter of the thesis (see section 3.2.2), a motivation is a condition that energises behaviour, gives it direction and determines how an individual will act in a certain situation (Kuhl 1986; Smith et al 2003). The participants in this study did not perceive their symptoms as threatening and as such were not motivated to seek medical assistance leading to presentation delay. This is because perceiving symptoms is more complicated than it may seem (Morrison and Bennett 2006; Sarafino 2006). According to Sarafino (2006) people generally perceive their internal state on the basis of physical sensations and are therefore more likely to notice strong sensations than weak ones. In spite of this, they often do not assess their internal states very accurately and also have trouble perceiving external symptoms, such as whether a mole like lesion is a MM. It is partly because of this low degree of accuracy in assessing signs of illness that the point at which individuals recognise a symptom differs from one individual to the next. Furthermore, people do not always notice symptoms, even strong ones, because of the amount of attention they give to their internal and external states (Pennebaker and Skelton 1981). Pennebaker and colleagues showed that a person's awareness of their symptoms depends on what else is going on around them. Thus, when their attention is engaged elsewhere individuals are unlikely to notice symptoms, especially subtle ones like MM symptoms sometimes are.

Although it is obviously important to recognise symptoms, there is ample evidence available in the literature to suggest that it is not necessarily enough to make people think they are ill and need to seek medical attention (Alder 1999; Oliveria et al 1999; Morrison and Bennett 2006). It would seem that a number of other perceptions have to be in place

before an individual recognises their symptoms as a health threat and takes action. According to the Health Belief Model (HBM see section 3.2.1 for more detailed discussion), individuals must first see themselves as being at risk of the threat. It is true to say where risk is perceived as minor or minimal the actions an individual will take are different from where risk is perceived as eminent and very real (Lupton 1999). The research participants did not report feeling vulnerable because of their symptoms which implies that they did not see themselves as being at risk of getting MM. Second, in order for an individual to take action, they must perceive the threat as being serious and believe that taking action will be effective. Results from the study indicate that because of the seemingly innocuous appearance of their symptoms, most participants often dismissed them as insignificant. This means that they did not perceive them as serious and as such did not believe that taking action was worth it. The HBM relies upon an understanding that the individual correctly perceives their health threat. What is evident from the results of this study is that through a series of inaccurate perceptions, the participants incorrectly perceived their health threat. As a result, they failed to appreciate the gravity of their situation and did not seek for medical attention.

Once a symptom has been perceived, in order for the individual to confer illness status and legitimise seeking professional help, they do not usually consider it in isolation but generally relate it to other aspects of their experience and to their wider concepts of illness. Illness representations are organised conceptions of individual illnesses acquired through the media, through personal experience and from family and friends (Leventhal et al 1997; Morrison and Bennet 2006). They can be vague, inaccurate, extensive or

detailed, but whatever they are, they influence how an individual facing symptoms or illness responds. Illness representations are thought to exist in memory from previous illness experience (generally common illnesses such as colds or flu), and as a result the perception of a new symptom may be matched to a pre-existing model or 'prototype' of illness that the person holds (representativeness and availability heuristics). These disease prototypes shape how a person perceives and responds to bodily signs and influences whether bodily signs are perceived to be symptomatic of illness or not.

Many different terms are employed, sometimes interchangeably, by authors discussing illness models for example; cognitive schemata (Pennebaker 1982); illness cognition (Croyle and Ditto 1990); common-sense models of illness and illness representations (Leventhal et al 1980; Leventhal et al 1984) and illness perceptions (Weinman et al 1996). One of the well-known models is the self-regulatory model of illness and illness behaviour: the 'common-sense model of illness' proposed by Howard Leventhal and colleagues (1992). This 'common-sense model' states that mental representations (heuristics) provide a framework for coping with and understanding illness and in an illness situation a person's response or behaviour is determined by these mental representations. Earlier work by Bishop and his colleagues (1987) supports this model and take it further by adding that people have pre-existing notions of the symptoms associated with common illnesses and self diagnose by comparing the symptoms they experience with those they expect for a given disease. Thus when symptoms present as expected, for example a lump in the breast in breast cancer (Burgess et al 2001) or severe chest pain in

myocardial infarction (Horne et al 2000) individuals use these heuristics to make a judgement about the cause of the problem and tend to seek help more promptly.

When it comes to MM, however, it can be argued that the same heuristics are not as effective. For example, as discussed in the sixth chapter of the thesis only three participants in the study had ever encountered a real melanoma so for the rest of them the mental representation of what a melanoma looked like was shaped by posters in the doctors' surgery, images on television or the internet, stories reported in popular magazines and imagination which seldom matched the reality. Illness behaviour; how individuals react in the presence of symptoms, is a highly individualised complicated process. As such, this thesis does not offer a full exposition of the topic; rather, it offers a selective view of the MM related illness behaviour of a particular group of research participants. The intention is to understand the challenges faced by this group of individuals and how these challenges might be more easily overcome thereby encouraging earlier presentation in MM patients.

#### NON-PHYSIOLOGICAL RELATED PERCEPTIONS

Findings from the study show that there are other non symptom related challenges that also play a significant role in presentation delay. These challenges are of a social nature and linked to how individuals live their lives and perceive themselves and others around them. They include how individuals perceive their roles and responsibilities, their gender and how they perceive medical services. Again, as with the symptom related perceptions, these factors are not a comprehensive list of all the non-physiological challenges that

might cause individuals to delay but rather specifically refer to the group of patients interviewed during this research with a possibility of being applicable to other MM delayers. Although it was not possible to conclusively determine where these perceptions originate from, one possible route of inquiry seems to be how these individuals are socialised.

The concept of socialisation figures prominently in sociology, underlying many of the discipline's major claims about the nature of society and social relations (Bennett and Watson 2002; Zerilli 2007). In general terms, socialisation is a generic concept used to explain the process by which individuals learn and perform the general competencies required for survival and participation in society (Cohen and Kennedy 2007; Zerilli 2007). Across the world there are numerous societies, each with their own culture and way of living. Each has some understanding of the adult proficiencies needed for adequate functioning and according to Matsumoto and Juang (2004) people are socialised in a way that promotes the specific skills needed for them to be accepted by their society and perform within it. On a personal level socialisation refers to the social and cultural shaping and development of the mental, emotional and behavioural abilities of individuals (Zerilli 2007). At a societal level, it helps to explain how and the extent to which a number of people can come together and successfully co-operate and adapt to the demands of social life (Long and Hadden 1985).

Three major theoretical approaches to socialisation are often considered in the literature. These are role-learning theory, social construction theory and psychoanalytic theory.

Although these three theories are often presented as rival theories, they actually contribute different components to the understanding of socialisation and although there are many points on which they disagree, their central insights are complementary viewpoints on a highly complex phenomenon (Bennett and Watson 2002; Cohen and Kennedy 2007). According to role learning theory socialisation is, above all, the process through which individuals learn how to perform social roles. It stresses the importance of role behaviour in social life and, therefore, the need to learn role expectations. On the other hand, social construction theory is part of the wider framework of symbolic interactionism and gives more attention to the formation of the self through social interaction. The third theoretical approach to socialisation considered in the literature is psychoanalytic theory which pays particular attention to the unconscious aspects of the mind and to the ways in which emotional forces drive people towards particular patterns of action throughout their lives. Whatever approach to socialisation one chooses to accept, the important thing to note is that how people are socialised undoubtedly affects their perceptions and actions.

For example, one of the most interesting non-physiological factors identified as being responsible for presentation delay in this study is how individuals perceive their gender. In the literature there is an abundance of research has been conducted by sociologists, psychologists, social psychologists, cultural theorists, anthropologists, and educators regarding male and female identity. Freud and later psychologists developed the psychoanalytic approach, concentrating on how early childhood experiences affect people's identities (Edley and Wetherell 1996). Cognitive-developmental theorists such as Kohlberg (1966) suggest that there are critical events that have a lasting effect on gender

identity development that are cognitive in origin. Role theorists, such as David and Brannon (1976), attempt to understand male identity as a collection of socially defined roles and behaviours. Although the focus of each school of thought varies slightly, an overall review of the literature on gender shows that most of the approaches attempt to understand it from a socialisation perspective. In this sense, whatever their origin, femininity and masculinity are not innate but are based upon social and cultural conditions. As such, it can be argued that how men and women are perceived, and indeed how they perceive themselves is defined by their cultural heritage and society.

In western culture, stereotypically, men are perceived as aggressive, competitive and instrumentally oriented while women are often depicted as passive, cooperative and expressive. Typically, gender roles portray women investing in the domestic role and men investing in the worker role (Eagly 1987) and although much has changed in the last few decades these stereotypes remain somewhat true. For example research has found that although men's participation in domestic labour has increased, women still perform between 65 and 80% of domestic chores in western societies (Bianchi et al 2000; Coltrane 2000) and women, more than men, still value jobs that do not require long hours of work and provide them with the flexibility to be able to balance work with family demands (Konrad et al 2000) Such observations and findings are particularly interesting when examining the problem of presentation delay because they imply that how men and women perceive their masculinity or femininity determines their help seeking behaviour.

Since the 'authentic' male is often portrayed as being tough, unemotional, physically competent, competitive and aggressive (Lee and Owens 2002), it is not surprising that findings from the study indicate that some men perceive asking for help as a threat to their male pride and machismo and find admitting to pain or any other problems as a confession of being weak. As a result of such stereotypes, there appears to have been a reluctance to seek medical help for their symptoms fearing ridicule and rejection from other men and indeed women in their social circles. In like manner, the findings discussed in section 7.1.1 indicate that devoting time and attention to the needs of other people over their own was commonly reported among the women in the study. It would appear that women are at the centre of family and social life performing certain social roles and functions and might find it difficult to divert their attention to their own needs. Other qualitative studies, mainly in breast cancer have also reported the tendency of women to devote their time and attention to the needs of others before attending to themselves (Mor et al 1990; Burgess et al 2001; Facione et al 2002). Burgess et al (2001) found that some women who cited domestic problems as a reason for delay were aware that their symptoms might be serious but nevertheless felt too busy to arrange a medical appointment.

Understanding the social context of the study and how people are socialised made it easier to understand certain behaviours and how they can be modified to improve outcomes. For instance, how participants perceived and reacted to their social responsibilities and commitments and how they perceived the doctor and medicine in general all seem to have been born out of their socialisation. In the UK, for example, medicine is socialised in the sense that the NHS is a publicly funded body and freely provides healthcare for all. As



such, perceptions of how it should operate, expectations and access will differ from a society where health care is scarce or has to be paid for. Furthermore, believing that the doctor 'knows best' or 'must not be bothered' alongside a desire to be a good patient can often explain the reluctance of some individuals to query reassurances given by the doctor or seek medical help.

From the discussion presented above, one of the main outcomes of the study is the realisation that presentation delay in MM does not have a universal cause but rather is like a journey with passport controls that the traveller has to navigate and negotiate before they can be allowed to enter the country of their destination, in this case the destination being diagnosis and treatment. Sometimes, as illustrated by the group of non-delayers, the journey is straightforward and the destination more easily accessible. At other times, however, the journey can be quite protracted and more difficult to negotiate. The case study presented below illustrates how this can happen.

## 8.6 PAT- A CASE STUDY

Pat (interview 14) a 68 year old keen gardener noticed a 'new mole' on her arm one day when she was out in the garden

Pat I remember thinking 'how strange, when did that get there?' because I had never really seen it before

This was the moment she **detected an unexplained symptom.**

Idah Well did you have any idea what it might be? Did you know what it possibly was?

Pat Not really (laughs) just thought funny little thing. I had no erm suspicions as to what it might be

Idah At this time, when you noticed it for the first time, the funny little thing, did you have any knowledge about MM?

Pat Yes to an extent, I guess, well.... maybe not. I always knew to put on cream to 'protect myself from cancer' but to be perfectly honest I don't think I ever actually gave it much thought, I mean I never really stopped to think about it and what I knew about it

From her responses it was clear that although she had possibly heard of MM, Pat had **insufficient knowledge** to adequately assess her symptom, never mind seek medical help.

Although Pat seemed unconcerned about her symptom Tversky and Kahneman (1974) argue that it is part of human need to create meaning from experiences- no matter how seemingly insignificant. As such, in the face of uncertainty Pat unconsciously turned to **heuristic thinking** to establish the 'meaning' of her lesion.

Pat I looked at it and it looked like just an ordinary mole so I thought it must be a mole [**representativeness heuristic**]. Besides I am covered with freckles and moles so it was not really surprising that I'd got another one [**availability heuristics**] and to be perfectly honest at my age one expects these things, I mean, my skin isn't as flawless as you young 'ins! So that, in a sense, set my mind at ease and I thought no more of it for a time [**low perception of risk and perception of symptoms as not serious**]

Although the words above may seem insignificant, in a lot of ways they describe how delay is created. Through heuristic thinking Pat misinterprets her symptoms. She assesses her lesion and uses both representativeness (it looks like a mole so it must be a mole) and availability (relying upon her knowledge of the freckles and moles she already has rather than examining other alternatives) heuristics. Having applied heuristic thinking, Pat feels confident about her 'diagnosis' and convinces herself that there is nothing wrong with her; therefore her perception of risk and the seriousness of the symptoms is very low. So unconcerned is she that she does nothing about her symptom for nearly a year. Within this

time, her 'mole' has grown and now has an irregular border but she still does nothing because she is *sure* it is just an ordinary mole

Pat Change in any way? I suppose it did, yeah a bit because my husband commented on it one day when we were cleaning the pond. Well I must say that surprised me because he never notices anything, you know, these men! Blind as bats most of the time! Anyway he said.... Erm... can't quite remember his exact words..... erm... well something about it being... oh yes 'strange 'un that' and I looked at it and it sort of looked ....*odd*....but I wasn't, I mean now I know I should have known better but I was so *sure* there was nothing wrong with it.

Pat uses a few interesting words such as 'odd' and 'funny little thing' to describe her lesion which suggests that even in her opinion it was different from other 'normal' moles but was still convinced that it is mole. This is an example for how individuals use the **anchoring and adjustment heuristic**. Pat under reacts to new information and fails to adjust her views because she has already 'anchored' her thoughts on the fact that her lesion is a harmless mole. Her low perception of risk also influences how she continues to live her **social life** and the things she does. Unaware of the growing MM, to celebrate their recent retirement, Pat and her husband go on a three month holiday to New Zealand to visit friends and family.

Pat On our first evening there, we are sitting outside having a drink when X, our host, it sounds so formal to call her that, X [her friend] and I went to school together many years ago and we have always kept in touch, anyway, keep focused Pat, anyway X turns to me and says what's that? We all look at it and I say 'well it's, well I think it's a mole', I think it was the way she asked I sort of well *lost confidence* you know what I mean? (laughs). Have you had it checked out? Have you been to the doctor? Well you need to go. I wish she'd stop because everyone is staring and I'm beginning to feel myself go all red and feel foolish for not going to the doctor, I looked to John [her husband] and I think he sees the pleading in my eyes because he says, firmly like, 'we did not think much of it but we will make an appointment when we get back to England' and that ended that but for the two weeks we stayed with her she kept going on and on about it. Even offered to take me to see her doctor but I knew we could not possibly afford it. I'll tell you one thing for nothing, when we landed I was off to the doctor's like a shot

Pat is finally triggered to act not by her symptoms but by **comments from a significant other**. Her story though unique in the finer details is resonant with other stories and illustrates how presentation delay can occur, how various perceptions and factors conspire to make it happen, often so insidiously that the delayer does not even notice their own delay. What is clear from the study however, is that protracted delay is not an integral part of everyone's journey. Six individuals interviewed during the later part of the interview process are described as non delayers and the difference between these two groups will now be considered briefly.

### 8.7 THE NON- DELAYERS- A different perceptive

Although the sample of non-delayers in this study is much smaller than the sample of delayers (six versus 36) there are some interesting insights to be gleaned from this group. Their journeys to diagnosis and treatment appear to have been rather effortless when compared to the delayer's journey. This is not to say the non-delayers did not face the same challenges as the delayers, rather it was they way that they handled the challenges that separates the two groups. The major difference appears to be their differing perceptions of the same situation. For as Covey (1989) comments perceptions govern the way we see things and the way we see governs how we behave. For example, the non delayers did not simply dismiss their symptoms as 'nothing' but rather viewed them as 'potentially something'. Thus even with the same level of knowledge there were those that considered the possibility that their symptoms might be something more sinister and acted upon their suspicions. It is possible that the non delayers were more aware of their increased risk and as such more alert to the possibility of developing skin cancer. Non

delayers appear not to have applied heuristic thinking as readily as the delayers and as such thought their symptoms through, often seeking validation from others and doing some preliminary research on their symptoms.

It is also interesting to note that the people who the non- delayers sought validation from all took them seriously and advised them to seek medical intervention. Although this sample is rather small and therefore caution has to be applied when interpreting the findings, it would appear that the experience of the non-delayers give credence to theories like Friedson's (1970) 'lay referral systems' (see section 3.2.5) and McKinlay's (1973) work on the influence of social networks on illness behaviour (see section 3.2.4). People close to the potential patient channelled their behaviour and facilitated access to care. It would seem that the non-delayer's family, friends and significant others had a positive perception of the process of seeking medical help and organised health care and these attitudes positively affected the non-delayers help seeking behaviour. This is most strongly illustrated by Colin (see section 6.3.3) and Andy (7.2) who would not have sought medical intervention of their own volition but because those closest to them perceived their symptoms as warranting medical intervention and as such they were 'forced' to enter the formal health care system.

The discussion presented above illustrates that there are no 'quick fix' solutions to the problem of delay. However, this is not to say individuals are destined to delay in presenting for help. Findings from this study show that early presentation is possible but is dependent on individuals having adequate knowledge, correctly perceiving their risk and

personal susceptibility, accurately interpreting their symptoms, how they are socialised and propitious social and life circumstances.

## **9. CHAPTER NINE**

### **ENHANCING EARLY DETECTION IN MELANOMA**

#### **9.1 INTRODUCTION**

Delayed presentation is one of the major challenges in melanoma care. It impacts on outcomes and determines the extent of primary treatment often resulting in unnecessary disabilities or even death. In the absence of more effective treatment for advanced tumours, early recognition and treatment of localised tumours is at present the most effective way of reducing mortality once melanoma has developed (Schmid-Wendtner et al 2002). A number of studies (Heard 2002; Hancock 2003; Phelan et al 2003) have indicated that there is definitely a greater role for nurses and other health professionals to play in enhancing the early detection of MM. This chapter will examine some of the ways this can be done. It begins by identifying two challenges that may be a barrier to early detection and how they can be overcome. This is followed by recommendations for clinical practice and further research and an outline of the study's limitations. The chapter concludes with the author's reflections on conducting the research project.

#### **9.2 POTENTIAL CHALLENGES**

##### **9.2.1 ACKNOWLEDGING PERSONAL RISK**

One of the greatest challenges potentially facing health care professionals in trying to enhance early detection in MM is getting individuals to recognise and acknowledge their

own personal risk. Studies of optimistic bias show that people generally consider that others will experience negative events sooner than they personally will. For example, in a study of young adults Clarke et al found that they often estimate the age of onset of skin cancer as later for themselves because skin cancer is perceived to have a delay of onset. Perceived delay of onset refers to an individual's belief regarding the length of the time between engaging in a risky behaviour and the occurrence of the negative event or outcome associated with that risky behaviour (Kos and Clarke 2001). The occurrence of an event is seen as having a long delay when there is a long time span between a risky behaviour and the consequence of that behaviour. For example, there is often a fairly lengthy time period between sunbathing without protection and getting skin cancer (Moore and Rosenthal 1992).

It is true to say where risk is perceived as minor or minimal the actions an individual will take are different from where risk is perceived as eminent and very real. The results of the present study suggest that people perceive their risk of getting a MM as less than other people of their age and sex. This low perception of risk may affect their self-protective and risk-taking behaviours (Weinstein 1989; McKenna 1993; Horswill and McKenna 1999), as well as their response to health promotion messages. That is, if people believe that their risk of getting a MM is lower than the risk of others, they will probably pay less attention to their sun related behaviour. Furthermore, if they do not acknowledge their own susceptibility to MM, then educational campaigns, such as Sun Smart campaigns, will be ineffective in changing their behaviour. Similarly, if someone thinks that they are unlikely to get a MM, then they may not be motivated to engage in behaviours that decrease the likelihood of getting this type of cancer (e.g. wearing protective clothing, avoiding the sun



during its peak hours, wearing high factor sunscreens). Believing that their chances of getting a MM are minimal, then individuals may also be less inclined to engage in activities which can lessen the severity of the impact if MM was to occur (e.g. regularly performing self skin examination to catch MM early in its trajectory).

The illusion that people do not need to protect themselves from something that is not going to happen anyway may also adversely affect campaigns aimed at increasing precautionary behaviour. For example, the information provided in mass media campaigns, such as the Sun Smart campaign run by Cancer Research UK and other sun awareness campaigns sponsored by the Department of Health and other organisations may not be heeded by the at risk population, because they may see the messages portrayed in these campaigns as being directed at people who are more vulnerable than themselves. According to Kos and Clarke (2001) the effectiveness of these campaigns may be improved if they emphasise that although people may have the *ability* to control the risks of negative events, the risks of experiencing such events can only be decreased if this control is *exerted*. That is, individuals generally have the *ability* to control the risks of developing MM by taking sensible precautionary actions like the ones outlined above, however, their risk of developing MM will not decrease unless they actually engage in these risk-decreasing behaviours. Further, the extent to which the majority of people engage in these behaviours needs to be more strongly emphasised.

### 9.2.2 TARGETING MEN

Another potential challenge facing health care professionals trying to increase MM awareness and promote early detection is how to reach men. Throughout the thesis there

have been undertones of the challenges linked to men's health. In chapter one it was established that although more women are diagnosed with MM mortality rates are nearly twice as high in men (see section 1.4.2). In chapter two a review of the literature on MM presentation delay identified gender as one of the most powerful socio-demographic factors in predicting delay. By and large, men were found to delay more frequently than women (see section 2.4.1). In the seventh chapter of the thesis, 'being a man' was found to be one of the major contributory factors in delayed MM presentation (see section 7.1.2). The key issue to arise from these discussions is that men appear to be reluctant to seek help for their MM symptoms. Having said this, delayed presentation in men is not a new story unique to this thesis. Indeed several authors such as Addis and Mahalik (2003); Galdas and his colleagues (2004); White and Banks (2004) and O'Brien and colleagues (2005), just to name a few, have written about the challenge of delayed help seeking behaviour in men across a wide range of contexts and illnesses.

Interestingly, the low rate at which men seek help has only been recently flagged as a problem. According to Courtenay (2000), in the past men's utilisation of health services was perceived as appropriate and not problematic whereas women were considered to be over utilising health services. As such, despite the rapidly growing body of work around men's health and consistent evidence that men are more likely to delay in seeking help for their symptoms, much work still needs to be done to establish why this is so. As a consequence there has been a limited amount of information on developing appropriate strategies on how to reach men. Encouragingly this is beginning to change with more resources such as an excellent book edited by Conrad and White (2007) *'Men's health-*

*how to do it'* based on the work of the highly acclaimed Bradford Health of Men Services being available to give practical guidance to individuals who want to successfully set up and deliver health services aimed at men and boys.

At the most basic level, White and Banks (2004) argue that in order to address help seeking in men and the problems of late diagnosis, health care professionals need to be better educated about the gendered aspects of health and illness. A better understanding of the dynamics involved in men's health may be beneficial in reaching earlier diagnosis (White and Banks 2004). For example, it is possible that men suffer from 'sex role strain' (Gailbraith et al 2001). This strain occurs when men are encouraged to live up to standards or norms for masculinity regardless of the physical or psychological strain produced (Gailbraith et al 2001). However, unless a health professional understands such issues and deals with them sensitively, then any efforts made to reach men may be unfruitful. Similarly, Nicholas (2000) suggests that willingness to seek medical intervention may be lessened due to the 'be tough' and 'be independent' cultural imperative men face. As a result of this, male cancer patients may be at a higher risk of being diagnosed later, receiving inadequate support and positive psychosocial adaptation is less likely. Nicholas (2000) suggests that in order to combat this problem, studies of cancer patients should include such masculine gender variables including role stress, attitudes towards masculinity, and personality traits. These factors must be considered in relation to differences in seeking help, coping and psychosocial adaptation.

From the findings presented in this thesis and the literature, it appears that men and women have rather different strategies for seeking help, utilise different resources and vary in their uptake of health services. Research has repeatedly shown that women are generally more aware of their bodies, have higher knowledge levels, pay more attention to symptoms, and perform more timely help seeking than men (Shilton 1999; van Osch 2007). This suggests that women may have an important role to play in assisting men to present earlier for diagnosis and treatment. It was also interesting to note that in the study the number of men that went to the doctor because a woman, mainly their partner, had '*made*' them go was significantly higher than the proportion of women who had gone on a man's insistence. In a now dated study Rampen et al (1989) also found that men required a stimulus to seek help for their MM symptoms from someone else more often (42%) than women. The conclusion that can be drawn from these findings is that women generally notice changes in moles more quickly than men and often do not require the same level of input from someone else to make them seek medical advice. Ideally, men should become better at managing their own health and well-being (White and Banks 2004) and should not expect women to be responsible for their health. However, as Holdroyd (2002) and White and Banks (2004) point out, in the meantime women are a valuable resource that can be used to assist health professionals to encourage earlier presentation in men.

Having said this, it is important to point out that men's health is different from women's health. As such, health care needs to be more focused on men and their specific needs in a way that is accessible to them (Holroyd 2002; White and Banks 2004). If health promotion initiatives for men are to be successful then health care workers at both a local and

national level need to depart from the ‘one model fits all’ approach and find more innovative approaches to address the health needs of men. This is not, of course, to suggest that since men are reluctant to seek professional help women are not, an assumption that is noted by O’Brien et al (2005) as being widespread and often implicit. Rather, the purpose of this section is to highlight that ‘these constructions of masculine “practice” raise particular barriers for men to the effective and appropriate use of health services and other forms of help-seeking (O’Brien et al 2005 p.515)

### 9.3 RECOMMENDATIONS FOR PRACTICE AND RESEARCH

Findings from the study indicate that there is a need for continued health promotion and education if delayed presentation in MM is to be curbed. However, presentation delay is not a universal problem as some individuals do present early and as such health promotion initiatives need to be targeted to those individuals identified by studies such as this one as being at an increased risk of delay behaviour. Furthermore, in the UK today there are multiple health promotion initiatives ranging from calls to eat five fruit and vegetables a day to the dangers of passive smoking. As such, information overload in the general public may be a challenge that has to be considered. In order to prevent health promotion messages encouraging early presentation in MM from ‘falling by the wayside’, they have to be relevant otherwise they stand in danger of becoming ‘just another’ message with minimal impact. What is required are innovative interventions that engage people in a participative process and address factors of personal relevance rather than those that simply aim to raise awareness or impose changes (Gonzalez and Lorig 2001; Ogilvie et al 2004). An example of such an innovation would be distributing sachets of sun screen and

talking to people about mole checks at the airport during the summer months when people are going abroad for their holidays and waiting for their planes. This would probably be more effective and relevant than if it was done than on a busy inner city street or even a medical centre during the winter months. Another innovative approach that might be tried would be to reach people where they are rather than in the formal health care settings that traditionally have been used. For instance, trying to reach men at the local GP's surgery or pharmacy may be ineffective they are widely recognised as not utilising health services to the same extent as women (Wyke et al 1998; Macintyre et al 1999; White 2007). As such, it may be necessary for health promoters (who are often nurses) to leave their comfort zones and engage with men in their places of work and recreation like factories and pubs. Equally since women may be too busy to attend health centres every effort must be made to reach them where they are. This may be in places like mother and toddler groups. Interventions need not be formal or lengthy but a level of creativity is required to make interventions effective. It is difficult to change longstanding and complex patterns of behaviour so any evidence that some targeted interventions have achieved any measurable shift would be encouraging.

As previously noted (see chapter one), there has been consistent progress over the past decade or two in reducing MM presentation delay. Maintaining and building on this progress will require continued and improved efforts at raising public awareness of the early warning signs and improving the diagnostic accuracy of doctors. It will also require expanding the healthcare system's ability to expertly respond to a growing demand for diagnostic services. Structured programmes of patient education would be beneficial in

reducing presentation delay and improving treatment outcomes. Early signs of MM such as increase in size, colour change and elevation of the lesion often do not stress patients or elicit help seeking behaviour thereby increasing the period of delay (Richard et al 2000; Negin et al 2003). Previous education efforts have emphasised these early changes in moles but this may not be the best strategy because tumours grow slowly and may not be noticed by the patient. According to Abbasi et al (2004) a better alternative would be for clinicians to place more emphasis on the inherent characteristics of MM. Classically, the "ABCD" mnemonic (see Table 1.3 in section 1.5) has been used to describe the most common characteristics of a melanoma. Abbasi et al (2004) advocate for the increased use of this mnemonic to educate the public and the non-dermatology and dermatology community about the key features of MM since it is a simple, succinct and memorable tool. In addition, judging from the responses of the research participants, general awareness of MM appears fairly high and as such more emphasis should be given to educating people about the less well known aspects of MM. For instance, although quite a large number of participants had regularly burnt as children, they did not know that this put them at an increased risk of getting MM. Had this information been made more readily available, perhaps more of them would have appreciated their increased risk.

Much progress has also been made in the diagnostic accuracy of doctors (Carli et al 2004; Ek et al 2005). As gatekeepers of the health service GPs have a special role to play in the reduction of MM presentation delay. Given the miniscule amount of time spent training them in melanoma diagnosis and the infrequency with which they are confronted with melanomas, the progress that has been made is substantial. Nonetheless, significant

additional progress is warranted. This may be accomplished by the application of simplified triage techniques for skin lesion evaluation by GPs (Carli et al 2005; Argenziano et al 2006). Furthermore, provision of technical aids such as cameras and dermatoscopes in GP practices might increase their skin cancer diagnostic abilities by raising interest and confidence (Argenziano et al 2006).

Although continued improvements in public awareness and doctors' diagnostic ability are clearly necessary, they are insufficient to address the problem of MM presentation delay. As the majority of melanomas are self-detected and many occur on parts of the body that are infrequently visualised, thorough skin self-examination has great potential for impacting melanoma presentation delay (Berwick et al 1996; Richard et al 2000a; Carli et al 2003). This intuitive conclusion is supported by cross-sectional data (Berwick et al 1996). Accordingly, existing efforts to teach the public skin self-examination should be expanded. One way of doing this would be ensuring that teaching about melanoma and effective skin self-examination (SSE) are an integral component of nursing care (Phelan et al 2003) particularly in primary care settings. As Oliveria and her colleagues (2001; 2002) discovered, interventions by nurses in promoting skin self-examinations have been effective and with proper training, nurses can be useful in identifying and triaging suspicious lesions.

Another way of teaching SSE could be the use of formal melanoma screening programmes. Formal melanoma screening is currently not undertaken in the UK possibly due to a lack of hard data supporting its utility in reducing melanoma mortality.



Preliminary data from an Australian study support the potential utility of screening programmes for improving the recognition of early lesions (Aitken et al 2006). In America a voluntary national programme for skin cancer screening coordinated by the American Academy of Dermatology has detected many melanomas (Geller et al 2003). From the evidence presented above, health care providers might consider introducing a programme of formal MM screening in the UK as well.

In order to maximise the benefits of MM prevention strategies, it would also be reasonable to follow the example of countries like Australia that have managed to reduce their incidence and mortality rates over the years. There health education is started early in a child's life so as they grow they can adopt attitudes and practices that minimise UV exposure. Studies have demonstrated that even pre-schoolers can learn and practice behaviours that reduce UV exposure (Loescher et al 1995; Buller et al 1996). Further evidence suggests that in order to change a child's attitude and their practices, their parents must first adapt more healthy sun related behaviour (Rodrigue 1996; Kristjansson et al 2003; Turner and Mermelstein 2005). For example, in a study assessing sun related knowledge, stage of change and psychological characteristics of parents with young children, Turner and Mermelstein (2005) found that the strongest predictors of child sun protection were parents' own sun protection habits.

#### FURTHER RESEACH

This study is one of only a few studies to examine the problem of presentation delay in MM patients from a qualitative perspective. The paucity of research concerning

presentation delay in MM patients means that many of the variables relevant to the concepts of this phenomenon are yet to be identified. As such it is recommended that later projects can use the results from this study to test, verify or extend the qualitative hypothesis that have emerged from this research. More specifically, in order to enhance early detection it would be astute to study the experiences of those who have not delayed in presenting for help. As such the experiences of non-delayers should be examined more closely. For example, although the sample of non-delayers in this study was small, there is an indication that their social networks may have significantly contributed to their earlier presentation. Future investigations could also focus on testing known models and theories of illness behaviour such as Freidson's (1970) lay referral systems and the Health Belief Model (Rosenstock 1966; Becker 1979; Becker and Rosenstock 1984) in MM patients. Results from this type of research could then be used to refine models to increase their predictive power in MM patients and target interventions that will help to reduce delay.

In addition, there were two under explored issues presented in the eighth chapter of this thesis that would benefit from further research. The first relates to the support needs of MM patients, both pre and post diagnosis. While there is a sizable body of 'support' literature available, only one study was identified that specifically examined the support needs of MM patients and yet the findings from the study suggest that receiving adequate levels of support was very important to patients. The second issue relates to survivorship in MM patients. Although receiving a MM diagnosis was often not life threatening, the limited findings from the study indicate that there may be residual issues that patients have to address and cope with even after they have been 'cured'. In the light of the rapidly

increasing incidence of MM, even if there is a drop in mortality rates, health care workers will still need to support an increasing number of patients post treatment. As such further research is required to understand the issues around MM survivorship to build on the evidence of this study.

## 9.4 LIMITATIONS OF THE STUDY

### 9.4.1 SINGLE INTERVIEWS

The first limitation was that this study relied on a single interview, rather than on multiple sequential interviews that would have formed a stronger basis for creating a nuanced understanding of social processes (Charmaz 2003). According to Charmaz (2006) and Strauss and Corbin (1998) ‘one shot’ interviews can undermine grounded theory (GT) research because the logic of the GT method calls for the emerging analysis to direct data gathering, in a self-correcting, analytical expanding process. Earlier leads shape later data collection. For instance, the interview guide was modified as data collection continued. New questions arose as more people were interviewed and a greater understanding of their situations achieved. A useful way to check leads and refine analysis would have been to go back and ask earlier participants about new areas as these were uncovered. As it happened, this study was designed as part of my PhD qualification and therefore constrained by time limits and in order to mitigate these challenges later interviews covered probing questions that addressed emergent theoretical issues. In addition, since self-detection and delay data mainly depend on the memory of patients, the possibility that some recall bias occurred during this study cannot be totally excluded. This may be a disadvantage of studying self-detection and delay.

#### 9.4.2 STUDY SAMPLE

Another limitation of this study was that data was collected from people who had eventually sought professional intervention for their symptoms and did not, therefore, include data from those who were yet to seek or chose not to seek medical advice. These may be the patients with more advanced and more serious disease who need the health education the most. This data would only be obtained from a house-to-house survey and not possible within the scope of the current study. Furthermore, the study sample was relatively small. Forty-two interviews were used in this study. However, even in large qualitative studies it is rare for there to be more than sixty in-depth interviews (Britten 1995). Commenting on the amount of data gathered during grounded theory research, Strauss and Cobin (1998) and Charmaz (2006) suggests that the researcher knows when they have enough data because the same stories appear again and again (theoretical saturation) and therefore the actual number of interviews or observations may be less important than the quality of the data. This was certainly the case in this study as common themes and stories started emerging and influencing the course of the interview process early within the interview period.

#### 9.4.3 INHIBITIONS

It is possible that the participants were selective in their descriptions of their life styles. In a society where alcohol abuse is rampant only a few individuals admitted to drinking alcohol regularly and two admitted to smoking. It is possible that forty individuals who did not drink or drunk very little and did not smoke could have been randomly selected, but I felt that those who did smoke and drink on a regular basis alcohol probably wished to down play how much they smoked or drunk because smoking and alcohol consumption

can be sensitive areas. As Lee and Renzetti (1993 p. 4) note ‘sensitive topics are ones that seem to be threatening in some way to those being studied’. Most emphasised the importance of a healthy diet and regular exercise, while only a few admitted to not eating a healthy diet or taking regular exercise themselves. I noted with interest that some of those who claimed to be ‘healthy’ looked like they weighed more than they should for their height. Most were anxious to be seen as ‘careful around the sun’ often emphasising how they frequently used sun screen lotions and how they did not ‘sit out in the sun’. Since these issues were aspects of their illness, it is possible that some of the participants exaggerated their prominence in their lives but unfortunately there was no way to validate their accounts.

#### 9.4.4 RISKS OF INTERACTION AND INVASION OF PRIVACY

In spite of all the good intentions and efforts made to act in the participants’ best interests some invasion, as it were, occurred to the people involved. Munhall (2001) warns that there is a danger of researchers cajoling themselves if they refuse to acknowledge that no matter how laudable their aims there may still be a degree of inconvenience and discomfort in participating in qualitative research. Protecting their identity seemed to be the participants’ major concern. For example, feeling a bit threatened by what appeared to be a breach in the data protection procedures of the Trust, one woman rang me on the day she received the letter introducing the study in the post inquiring how I had got her contact details. This was in spite of the fact that the letter had been sent on a hospital letterhead and signed by the dermatology consultant. I had to explain to her that I did not know who she was because none of her details had been passed to me yet, and that if she did not want me to get her details she had to sign the objection slip and send it back to the consultant

who would remove her name from the list that would be eventually passed on to me. That seemed to reassure her and after asking a few questions about the study, she decided to take part, gave me her details and we arranged to have an interview on a later date. Even though the introduction letter explained that I had no access to their details and would only contact them if they did not object, some people still seemed a bit wary and on initial contact by telephone asked how I had got their details. I often had to reassure them that it was through the auspices of the Trust with the agreement of their consultant (who had sent them the letter) and research ethics committee and that not just everybody 'who walked off the street' (including me) could access their details.

Since interviewing is essentially a process of human interaction, all the potential risks of interaction, such as embarrassment, anger, violation of privacy, misunderstandings and conflicts in opinions and values may have arisen at some point of the project. Although no topic that can be distinctly described as sensitive, embarrassing or upsetting was discussed, some parts of the research process that probed personal feelings and actions may have been at least disconcerting and possibly distressing to some people. One man rang me a few days after the interview to clarify what I had meant when I asked a certain question. The intention of the question 'what was going on in your life at the time?' was to find out if there were any mitigating circumstances in his life at the time he discovered his lesion that might have contributed to his delay in seeking medical attention. At the time his answer had been 'nothing' and he had gone on to add that everything had just been 'normal'. I had been satisfied with the answer and had moved on to ask other questions so I was rather surprised by his call. In my opinion the question did not seem particularly

obtrusive. Nonetheless, his call prompted me to rephrase the question to; ‘could you describe the events that were going on in your life at the time?’ just in case it was also misunderstood and perceived as inappropriate by future respondents. As a safeguard, the telephone number of the skin cancer CNS was given to all participants in case the interview raised any issues they felt they would like to discuss further or did not feel comfortable discussing with me. As far as I am aware no one called the CNS after the interviews.

## 9.5 REFLECTIONS OF A NOVICE RESEARCHER

Conducting the research has been a challenging yet enlightening experience. As a nurse I now have an increased understanding of the challenges that individuals subsequently diagnosed with MM face that result in their delayed presentation. The next challenge is how to move beyond rhetoric and develop and implement strategies that lead to a reduction in the number of delayers. As a researcher I believe I have significantly developed on both a professional and personal level. The PhD studentship I was awarded has provided me with research training, for which I have been awarded a Postgraduate Diploma in Research Methods for the Social Sciences with Distinction, as well as the opportunity to undertake this sustained piece of original research. As a result of this research I have had one article published in a peer reviewed journal (see appendix 7) and been accepted to present my work at two international conferences. The opportunity to do the PhD qualification has helped me to progress from a novice who had never done any research before to a junior researcher who is more confident to undertake new projects in the future

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# APPENDIX

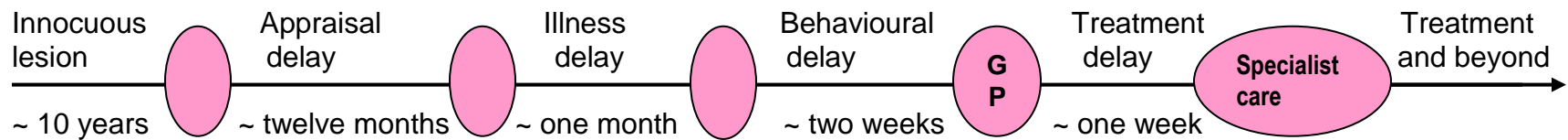
# APPENDIX 1

## PARTICIPANT PROFILES

### INTERVIEW 1

<b>Name</b>	Sue
<b>Sex</b>	Female
<b>Age range</b>	65-74
<b>Marital status</b>	Widow
<b>Occupation</b>	Housewife
<b>Skin Type</b>	I
<b>Hair Colour</b>	Strawberry Blond
<b>Eye colour</b>	Blue
<b>Breslow thickness</b>	1.4 mm

#### Presentation Journey

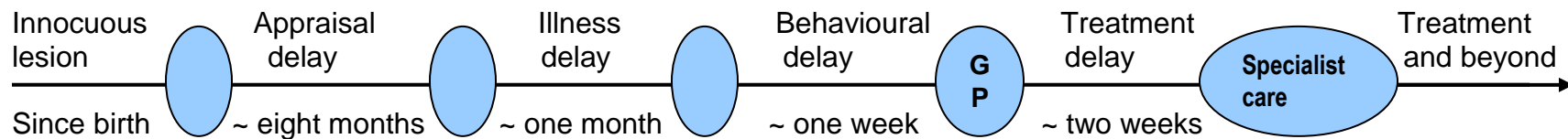


**TOTAL DELAY** = Approximately fourteen months

## INTERVIEW 2

<b>Name</b>	Paul
<b>Sex</b>	Male
<b>Age range</b>	35-44
<b>Marital status</b>	Married
<b>Occupation</b>	Outdoor worker
<b>Skin Type</b>	II
<b>Hair Colour</b>	Pale Brown
<b>Eye colour</b>	Green
<b>Breslow thickness</b>	2.4 mm

### Presentation Journey

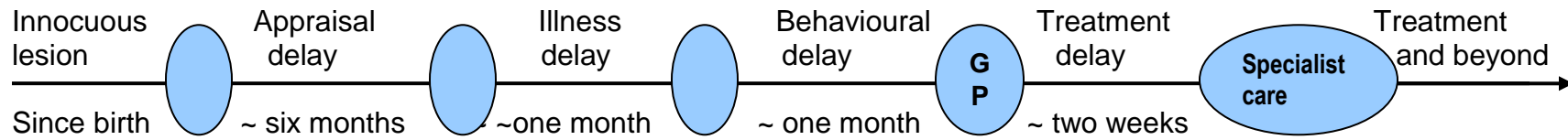


**TOTAL DELAY =** Approximately 10 months

### INTERVIEW 3

<b>Name</b>	Simon
<b>Sex</b>	Male
<b>Age range</b>	45-54
<b>Marital status</b>	Married
<b>Occupation</b>	Professional
<b>Skin Type</b>	III
<b>Hair Colour</b>	Medium Brown
<b>Eye colour</b>	Brown
<b>Breslow thickness</b>	2.0 mm

#### Presentation Journey



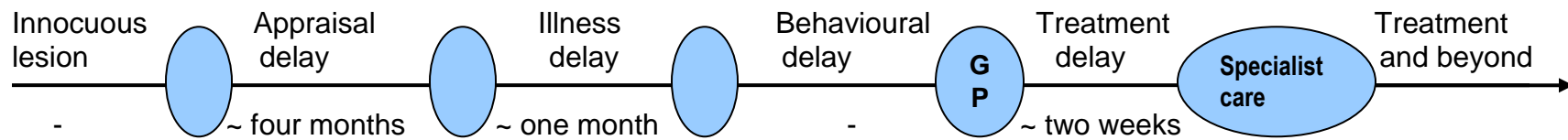
**TOTAL DELAY** = Approximately nine months



## INTERVIEW 4

<b>Name</b>	Luke
<b>Sex</b>	Male
<b>Age range</b>	75+
<b>Marital status</b>	Widower
<b>Occupation</b>	Retired Armed Forces
<b>Skin Type</b>	II
<b>Hair Colour</b>	Auburn
<b>Eye colour</b>	Green
<b>Breslow thickness</b>	2.3 mm

### Presentation Journey

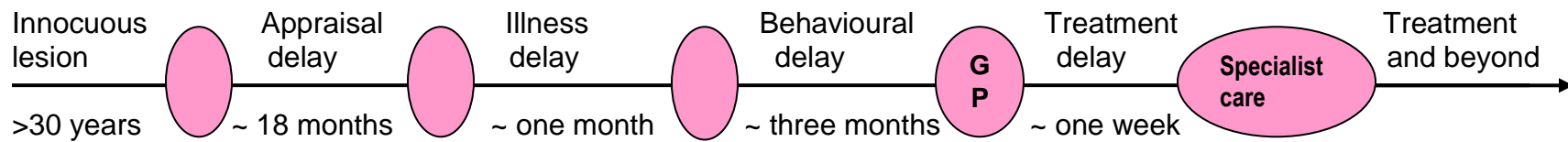


**TOTAL DELAY** = Approximately six months

## INTERVIEW 5

<b>Name</b>	June
<b>Sex</b>	Female
<b>Age range</b>	55-64
<b>Marital status</b>	Married
<b>Occupation</b>	Full-time Carer
<b>Skin Type</b>	III
<b>Hair Colour</b>	Pale Brown
<b>Eye colour</b>	Blue
<b>Breslow thickness</b>	1.9mm

### Presentation Journey

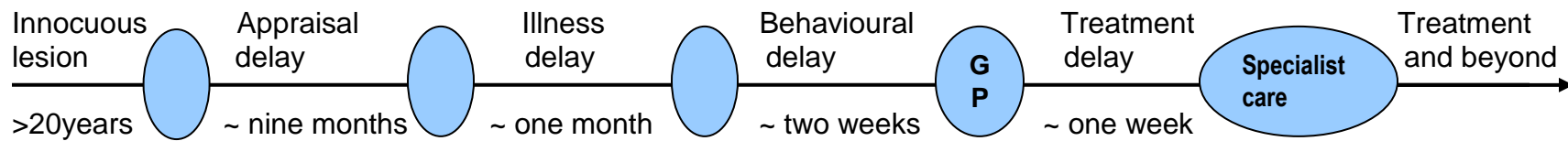


**TOTAL DELAY** = Approximately 22 months

## INTERVIEW 6

<b>Name</b>	Matthew
<b>Sex</b>	Male
<b>Age range</b>	65-74
<b>Marital status</b>	Married
<b>Occupation</b>	Self employed
<b>Skin Type</b>	II
<b>Hair Colour</b>	Red
<b>Eye colour</b>	Green
<b>Breslow thickness</b>	1.0 mm

### Presentation Journey

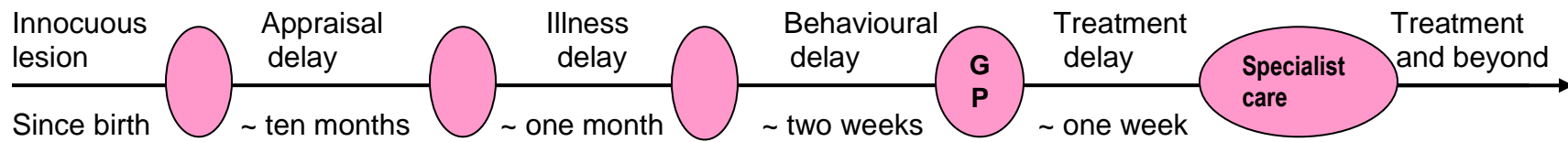


**TOTAL DELAY =** Approximately 11 months

## INTERVIEW 8

<b>Name</b>	Samantha
<b>Sex</b>	Female
<b>Age range</b>	25- 35
<b>Marital status</b>	Single
<b>Occupation</b>	Office worker
<b>Skin Type</b>	III
<b>Hair Colour</b>	Blond
<b>Eye colour</b>	Blue
<b>Breslow thickness</b>	2.6 mm

### Presentation Journey

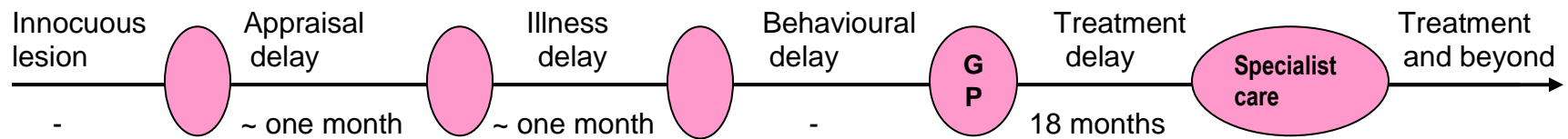


**TOTAL DELAY** = Approximately 12 months

## INTERVIEW 9

<b>Name</b>	Jane
<b>Sex</b>	Female
<b>Age range</b>	55-64
<b>Marital status</b>	Widow
<b>Occupation</b>	Health worker
<b>Skin Type</b>	II
<b>Hair Colour</b>	Reddy Blond
<b>Eye colour</b>	Bluey grey
<b>Breslow thickness</b>	6.2mm

### Presentation Journey

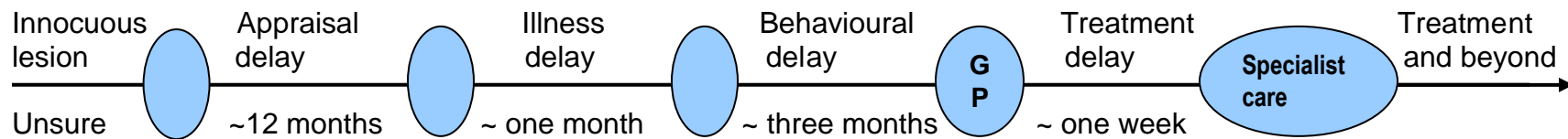


**TOTAL DELAY** = Approximately 20 months

## INTERVIEW 10

<b>Name</b>	Peter
<b>Sex</b>	Male
<b>Age range</b>	75+
<b>Marital status</b>	Married
<b>Occupation</b>	Full-time Carer
<b>Skin Type</b>	III
<b>Hair Colour</b>	Medium Brown
<b>Eye colour</b>	Blue
<b>Breslow thickness</b>	9.6mm

### Presentation Journey

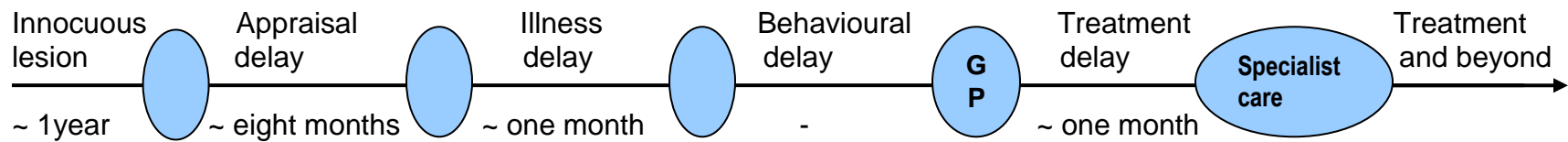


**TOTAL DELAY =** Approximately 16 months

## INTERVIEW 12

<b>Name</b>	Eddy
<b>Sex</b>	Male
<b>Age range</b>	65- 74
<b>Marital status</b>	Married
<b>Occupation</b>	Managerial
<b>Skin Type</b>	I
<b>Hair Colour</b>	Blond
<b>Eye colour</b>	Grey
<b>Breslow thickness</b>	3.2 mm

### Presentation Journey



**TOTAL DELAY** = Approximately 10 months

## APPENDIX 2

ORIGINAL RESEARCH PROPOSAL SUBMITTED FOR ETHICAL APPROVAL



# Project Proposal

## Presentation Journey To Specialist Care- The Pre-diagnostic Experiences Of People With Malignant Melanoma

Correspondence to:  
Idah Nkosana-Nyawata  
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Tel: 01274 \*\*\*\*\*  
Email: [i.d.s.nkosana@bradford.ac.uk](mailto:i.d.s.nkosana@bradford.ac.uk)

Principal Supervisor : Dr. Annie Topping  
Second Supervisor : Dr. Andrew Wright



**TITLE**

Presentation Journey to Specialist Care- The Pre-diagnostic Experiences of People with Malignant Melanoma

**KEY QUESTION**

What are the challenges, if any, that individuals subsequently diagnosed with malignant melanoma face that impede or facilitate their presentation for diagnosis and treatment?

**KEY WORDS**

Malignant melanoma; skin cancer; presentation delay; early detection; attitudes, values and beliefs

**RATIONALE FOR STUDY**

Malignant Melanoma is the most life threatening form of skin cancer and its prevalence is increasing at a rate that is greater than any other type of skin cancer, reporting a 24% increase rate in the United Kingdom in the last five years. Despite this increase, melanoma is a curable malignancy and survival prospects are associated with early detection. If caught early, the survival rate is over 95% (Cancer Research UK 2005). This indicates that early presentation is significant in terms of outcome. Currently, little knowledge seems to exist about patients' presentation journeys and why some individuals appear to delay in presenting with their signs and symptoms for diagnosis and treatment. Delay is particularly concerning considering the fact that the signs and symptoms caused by malignant melanoma can usually be recognised early enough for curative treatment to be carried out. This research is important because understanding why delay occurs and the factors that trigger people to seek medical attention for their signs and symptoms entails that service providers can improve the services they provide, implement more effective health promotion initiatives, prevent some traumatic modality treatments and ultimately save lives by preventing unnecessary deaths.

## METHODOLOGY

### RESEARCH DESIGN

Given the exploratory nature of the project, Strauss and Corbin's (1998) interpretation of the Grounded Theory (GT) methodology will be used. GT makes its greatest contribution in areas in which little research has been done and through data collection and analysis understanding (theory) can be generated in order to provide insight about a phenomenon. As stated before, there appears to be very little research that has been conducted specifically examining presentation delay in malignant melanoma. This makes GT an appropriate methodology for this project because the paucity of research concerning presentation delay in melanoma patients means that many of the variables relevant to the concepts of this phenomenon are yet to be identified and any theory that is developed through this study can be used in later projects to test, verify or extend the qualitative hypothesis that have emerged from this initial research.

### STUDY POPULATION AND SAMPLE

This study, like most other qualitative studies, will focus on a relatively small number of participants selected purposefully in order to permit an in-depth understanding of the phenomenon of presentation delay in malignant melanoma. It is hoped that approximately fifty people will agree to participate. The principle inclusion criteria in this study are men and women above the age of eighteen who have received a positive malignant melanoma diagnosis in the last three years and can speak and read the English language. Whilst an understanding of cultural differences is very important, participants who are unable to read, write or speak English will not be included in this study. It is anticipated that the largest percentage of the sample will be Caucasian, English speaking people as malignant melanoma rarely presents in darker skinned populations (Cancer Research UK 2004). Only adults over the age of 18 will be selected. Although it is most common in the over 75s, compared with other cancers, malignant melanoma incidence is fairly high in the young. It is the third most common cancer for 15-39 year olds. However, since the resources necessary to study children and adolescents are considerable and data collection is complicated by the need to adapt questionnaires and interviews appropriately it is

deemed justifiable to exclude children on these grounds. Potential participants who fulfil the inclusion criteria will be identified from electronic databases managed by the Dermatology Out Patients Department and the Skin Cancer Nurse Specialist.

Letters inviting potential participants to take part in the project will be sent out with addressed prepaid reply envelopes, a confirmation slip and an information sheet about the project (patient letter and information sheet attached). These letters will probably be followed up by a telephone call in case any of the participants have any queries before committing themselves to the project. Should they decide to participate, they can return the confirmation slip and make arrangements to be interviewed at a location and time that is convenient to them. Signed consent will be gained at the beginning of the interview after the participants have had the opportunity to ask any questions they may have about the study (patient consent form attached).

#### DATA COLLECTION AND ANALYSIS

The GT methodology does not follow what is generally regarded as a chronological order. Data collection and analysis will be linked from the beginning of the research, proceed simultaneously and interact continuously. Data collection will occur through a series of one- to-one semi-structured interviews lasting between forty-five minutes to an hour fifteen minutes. Interviewing will be done in batches of six to ten people at a time in order to allow the researcher time to analyse the data using constant comparison and carefully consider how any emergent themes can be explored in subsequent interviews. The interview and field note text will be imported into the NUDIST software management system. Analysis will begin after the first interview and become more intense as interviewing progresses. At the heart of GT analysis is the coding process which consists of 3 major types- open, axial and selective. Open coding is the examination of minute sections of text made up of participants' words, phrases and sentences. Through this process the researcher will be able to identify categories, their properties and dimensional locations in the data. Axial coding is the procedural step that follows open coding. Open coding disaggregates data so that categories can be located, then axial coding takes these

categories and relates them to their subcategories to form more precise and complete explanations about phenomena. Finally selective coding will commence. This is the process of integrating and refining the theory. It is completed at a higher level of abstraction to help define and develop the core category- the one variable central to the phenomenon under study. This essential element of the theory illuminates the main theme of the research and brings an explanation for what is going on in the data. Memos keeping a record of ideas about emerging categories, linkages and theories will be used throughout the study and will be stored within the NUDIST document system.

## APPENDIX 3

### LETTER FROM THE CONSULTANT DERMATOLOGIST

Name And Address

Date To Be Added

Dear Name of Patient

I am writing to invite you to take part in a research project. The purpose of the project is to investigate the experiences of people before they are diagnosed with malignant melanoma. We hope to find out whether these experiences can inform health promotion initiatives and improve services for patients.

If you are interested in taking part, please take time to read the information sheet provided carefully and if you wish, discuss it with friends, relatives and your GP to help you make a decision about being involved. You are also welcome to discuss the project with me if you feel that this will help you make a decision on whether to take part or not.

Participation in this research project is entirely voluntary and whether you choose to take part or not please be reassured that it will not affect the care you receive in any way. The principal investigator in this project is Idah Nkosana- Nyawata, a PhD student from the University of Bradford. You can contact her on 01274 23\*\*\*\* or by email at [i.d.s.nkosana@bradford.ac.uk](mailto:i.d.s.nkosana@bradford.ac.uk)

With your permission, I will pass on your contact details to her and she will contact you in about a week to make arrangements to interview you at a time and location that is convenient to you. If you do not wish to participate in this project, please return the enclosed objection slip in the prepaid addressed envelop and your contact details will not be passed on to Ms Nkosana- Nyawata, otherwise we will assume you are happy to be contacted with regard to this matter.

Thank you for taking the time to read this information. On completion of this project, a project report will be produced and the results are likely to be published in a professional journal. If you would like a copy of any of these please feel free to phone or email Ms Nkosana-Nyawata on the contacts above.

Best wishes

Consultant Dermatologist

## APPENDIX 4

### PATIENT INFORMATION LEAFLET



## Patient Information Sheet

### Presentation Journey To Specialist Care: The Pre-diagnostic Experiences Of People With Malignant Melanoma

You are being invited to take part in a research study. Your participation in this research is voluntary. Participation in this study has nothing to do with your clinical care and will not affect it whatever your decision. You may withdraw from the study at any time and without giving a reason

Before you decide, it is important for you to understand why the research is being done and what it will involve. This information sheet explains what we hope to achieve with the results of this study, how we hope to data and how you may be able to help us. Do contact us if there is anything that is not clear, or if you would like more information. The contact number is 01274 23\*\*\*\* or email [i.d.s.nkosana@bradford.ac.uk](mailto:i.d.s.nkosana@bradford.ac.uk). Please take time to decide whether or not you wish to take part.

### What Is The Purpose Of This Project?

In this project we are studying what motivates people who are subsequently diagnosed with malignant melanoma to seek medical attention for their signs and symptoms. Melanoma is a curable malignancy, if caught early, survival prospects are excellent. However, there currently is very little knowledge about the experiences of people before they are diagnosed with melanoma, what triggers them to seek medical attention and treatment and what challenges or barriers they face. In this study we are trying to identify those factors that make people more likely to seek medical attention earlier.

We are also looking at how we can improve the practical advice given to people before and/or after they are diagnosed with melanoma. Clearly, there is a great variation in how people react to their symptoms and an understanding of what informs a particular set of beliefs and consequent behaviour is therefore necessary not only to better understand why people do the things they do but also to improve service provision.

## **Why Have I Been Chosen?**

You have been chosen because you have had a melanoma diagnosed. We hope that approximately 50 people will agree to participate in this study. The consultant responsible for your care is working with us on this research study and we have been given permission to ask patients recently diagnosed with melanoma to be informed about the study.

## **Do I Have To Take Part?**

It is up to you to decide whether or not to take part. If you decide to take part, you will be given another information sheet and will be asked to sign a consent form. You will be given a copy to keep. If after deciding to take part you change your mind, you are free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

## **What Will Happen If I Take Part?**

It is up to you to decide whether or not to take part. If you decide to take part

1. You will receive a telephone call arranging an interview session with you at a time and location that is convenient to you. The interview will take about forty-five minutes to an hour and a quarter.
2. Before the interview begins, you will be asked to sign a consent form. You will be given a copy of this to keep.
3. We would like access to your relevant hospital notes for information on your medical conditions and treatments you may have had in the past, which may be important.
4. We would like your permission to pool your data anonymously with similar data obtained from others. None of the data will be attributed to you when it is pooled.
5. We would like, with your permission, to inform your GP of your participation in this study.
6. If you agree to take part in the study, we will seek permission to possibly contact you for a follow-up interview a few months after your first interview.

## **Will My Taking Part In This Study Be Kept Confidential?**

In the study, all the information that you give us, or that we obtain about you from other places will be confidential. All the information given will always be kept securely and anonymously to preserve confidentiality. At the end of the study we will analyse the information gathered from all the participants. The results are likely to be published in a professional journal. The results may be used in

planning services for other skin cancer patients within the trust. No patient will be identified in any report or publication.

## Who Is Organising The Research?

The principal researcher in this project is Idah Nkosana-Nyawata who is currently a PhD student at the University of Bradford, School of Health Studies. The project is being undertaken as part of the educational qualification. It has been reviewed by Bradford Teaching Hospitals NHS Foundation Trust Clinical Research Ethics Committee and the Bradford Teaching Hospitals NHS Foundation Trust Research and Development Office.

Thank you for taking the time to read this. We hope you will decide to take part in the study as we can only learn more about this aspect of melanoma with your valued help. If you have any questions please do not hesitate to contact

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Dr. Annie Topping (Head of Nursing)  
Research Supervisor  
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Email : [a.e.topping@bradford.ac.uk](mailto:a.e.topping@bradford.ac.uk)

Dr. \*\*\*\*\* (Consultant Dermatologist)  
Research Supervisor



## APPENDIX 5

### PATIENT CONSENT FORM



#### **Presentation Journey To Specialist Care: The Pre-diagnostic Experiences Of People With Malignant Melanoma**

This form should be read in conjunction with the Patient Information Sheets

I agree to take part in the above study as described in the Patient Information Sheets.

I understand that I am under no obligation to take part in this study and may withdraw from it at any time without justifying my decision and without affecting my normal care and medical management.

I understand that members of the research team may wish to view relevant sections of my medical records, but that all the information will be treated as confidential.

I agree to the provision of any significant information relating to my involvement being given to my General Practitioner and/or Consultant.

I have read the patient information sheet and this consent form and have had the opportunity to ask questions about them and discuss what participation in the research entails with.....

Signature of patient \_\_\_\_\_

Name in BLOCK LETTERS \_\_\_\_\_

I confirm that I have explained the nature of the study, as detailed in the Patient Information Sheet in comprehensible language to the patient.

Signature of Investigator \_\_\_\_\_

Name in BLOCK LETTERS \_\_\_\_\_

Date \_\_\_\_\_

I would like to receive information regarding the findings and progress of the research   
I would like a copy of the final project report

(PLEASE TICK IN BOX)

## APPENDIX 6

### INTERVIEW GUIDE

#### Demographic questions

- 1 Sex
- 2 Marital Status
- 3 Fitzpatrick Skin Types (I- VI)
  - I = always burn, never tan
  - II = burn and then tan very slightly
  - III = burn moderately and tan gradually
  - IV = burn minimally, tan easily
  - V = rarely burn, tan deeply
  - VI = never burn, tan deeply

#### Hair Colour

- 1 = red/auburn
- 2 = blond
- 3 = pale brown
- 4 = medium brown
- 5 = dark brown
- 6 = grey

#### Eye Colour

- 1 = blue
- 2 = green/hazel
- 3 = brown
- 4 = grey

- 4 Age (in range)  
15-24; 25-34; 35-44; 45-54; 55-64; 65-74; 75+
- 5 Employment status

#### Initial Questions

1. When, if at all did you first notice your lesion/mole
2. Tell me what happened.....
3. What was it like? What did you think then?
4. Can you describe the events that lead up to (or preceded) you going to your GP?
5. Who, if anyone, influenced your actions? Tell me how he/she/they influenced you
6. Could you describe the events that were going on in your life at the time?
7. How would you describe how you viewed 'skin cancer/ MM' before you were diagnosed? How, if at all, have your views changed?
- 8 How would you describe the person you were then? Has this experience changes who you are in any way?

### **Intermediate Questions**

1. What, if anything, did you know about MM before your diagnosis?
2. Where/how did you learn/ hear this?
3. As you look back from when you first discovered your lesion/mole are there any events that stand out in your mind? Can you describe it (them)? How did this/these events affect your course of action with regard to your lesion?
4. Who, if any, one was involved? How they involved?
5. What, if anything, triggered your visit to the GP?
6. What, if anything, hindered your visit to the GP?
7. What are your feelings about 'medical' settings? Do you feel positive or negative about visiting doctors?
8. How long did it take, after your GP had referred you, for you to see the specialist?

### **Lifestyle Questions**

9. Do you consider yourself to be a 'healthy' person? (Exercise, diet, rest etc)
10. Please give examples of things you do to keep 'healthy'
11. What about examples of unhealthy thing?
12. Do you smoke? How many a day?
13. Do you tend to seek immediately or put off seeing the doctor when you are not well?
14. How 'body' conscience or you? (looking in the mirror, grooming etc)
15. What are your hobbies? (Outdoor or indoor)
16. Who has been the most helpful to you during this time? How has she/he been helpful?

### **Ending Questions**

1. Could you describe the most important lessons you learnt from your experiences?
2. What have been your most positive (then negative) experiences in the NHS?
3. After having had this experience, what advice would you give to someone who has just discovered that he or she has a suspicious looking lesion?
4. What advice, if any, would you give to anyone planning a health promotion campaign for people who discover that they have suspicious lesions to present for help sooner?
5. Is there anything you might not have thought about before that has occurred to you during this interview?
6. Is there anything you have said to me today that you would like to rephrase or recant?
7. Is there anything you would like to ask me?

**APPENDIX 7**  
**RESEARCH ARTICLE**