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'I am not someone who gets skin cancer': Risk, time and malignant melanoma

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ABSTRACT

'Delay' is a term used in the cancer literature since the 1930s to describe the period between self-detection of a concerning sign of possible disease and presentation to a health professional. This linguistic choice carries an implication of blame for apparent failure to manage a risk appropriately, drawing attention away from the contemporaneous perspectives of those who respond to suspicious indicators more or less quickly. We present findings from a grounded theory study of accounts given by 45 patients about their slower or quicker journeys to a diagnosis of cutaneous

malignant melanoma, a cancer which can 'hide in plain sight'. There has been little research exploring in qualitative detail patients' perspectives on their decision-making about what subsequently turn out to have been signs of this most risky of skin cancers. The findings frame referral time-lapses in terms of normalisation of symptoms, sometimes buttressed by reassurance derived from health promotion messages, disconfirmation of patients' concerns by their general practitioners and prioritisation of other life concerns. We argue that a shared sense of urgency surrounding melanoma self-referral derives from a clinical representation of current knowledge which conceals numerous evidential uncertainties.

Keywords: delay, timeframe, categorisation, risk, perceived risk, risk management, cancer recognition, malignant cutaneous melanoma

“The past is a foreign country; they do things differently there.” (Hartley 1953:7).

Introduction

In this article we explore the experiences of patients living with cutaneous malignant melanoma with reference to temporal issues, extending the findings of a qualitative, grounded theory study (Nkosana-Nyawata, 2009). Our analysis examines the accounts given by patients who had not sought and/or received speedy treatment, comparing their understandings with those of patients who had been treated quickly. Little or no research has been done into decision-timing from the culturally contextualised perspectives of decision-makers themselves (Andersen *et al.*, 2010) in a field dominated by medical and quantitative psychological paradigms. Better understanding of the interpretive frameworks which individuals bring to bear on potential risk indicators for conditions such as cancer may have life-saving significance, although, as we will argue, considerable but under-acknowledged uncertainty exists about the risk-reducing benefits of early melanoma detection. Furthermore, such research can generate insights into the nature of societally organised time-consciousness, as will be seen in the often poignant accounts of patients living with advanced melanoma.

In the next section we will review the epidemiological risk background for cutaneous malignant melanoma, before outlining conceptual analyses and empirical research concerned with the timing of decision-making by and for people who might be deemed at risk of developing this condition.

Risk, time and malignant melanoma

Impact of time-lapses prior to treatment

Issues involving the timing of decisions to seek investigations about what turns out retrospectively to be a malignant melanoma need to be considered in relation to prevailing views about the epidemiological and clinical context. Two features of this cultural context are particularly relevant: firstly, the identification of a health crisis arising from a supposed 'epidemic' of this condition; and, secondly, the belief that time-lapses in the implementation of treatment carry avoidable life-threatening consequences. However, there is a degree of uncertainty, under-recognised in the medical and public health literatures, about the strength of the evidence for both the extent of any epidemic (Bataille and de Vries, 2008) and the efficacy in different sorts of cases of medical interventions such as local surgery and adjuvant therapy designed to control disease spread (Berwick and Wiggins, 2006). Regardless of their truth value, these two beliefs conjointly create an official sense of urgency, a temporal pressure in relation to primary and secondary prevention. These two complementary forms of risk reduction are to be achieved, according to the official public health script, through limiting length of exposure to ultraviolet radiation and regular self-surveillance of the skin combined with speedy responding to suspicious lesions.

Less common, but more life threatening than other forms of skin cancer, cutaneous malignant melanoma was, in 2010, the 18th most common cause of cancer death in the UK, accounting for only around 1 per cent of all cancer deaths, and the 19th worldwide

(Cancer Research UK, 2013). The present UK lifetime risk of developing melanoma is about 1 in 55, much lower than for other common cancers, for example, 1 in 8 for both prostate and breast cancer (Cancer Research UK, 2013), although all of these statistics contain unknown proportions of pseudo-disease.

Over the last 40 years, the incidence of non-melanoma and melanoma skin cancers has increased in many countries, a trend which has been likened to an epidemic (Erickson and Driscoll 2009, Levell et al 2009), and explained in terms of greater exposure to assumed risk factors, particularly increased UVF from more frequent holidays at lower latitudes and use of sun-bedsⁱ. The age-standardised annual incidence of melanoma appears to have increased inexorably over recent decades in many countries, with the reported UK rate going up from about 3 per 100,000 in 1975 to 17 in 2010 (Cancer Research UK, 2013). Such statistics create a sense of urgency about the necessity for primary and secondary prevention. However, some or all of this apparent increase may result from 'diagnostic drift' in which more intense surveillance leads to earlier detection of growths which might not have caused problems if they had remained undetected (Bataille and de Vries, 2008). Nørgaard, Glud and Gniadecki (2011) concluded from a review of studies involving over 2000 individuals and covering periods from 1964 to 2006, that increases in melanoma incidence were largely confined to thinner, less risky forms, and had not been matched by greater mortality rates except among older men. Age-adjusted mortality rates increased in the USA by about 1.5 per cent per annum in the USA between 1977 and 1990, but then began to decline (Marcovic et al., 2007).

However, the clinical literature sometimes conveys a much more alarming picture of rapid growth in melanoma mortality risk. For example, the UK Melanoma Taskforce (2012, p. 9) report, *Quality in Melanoma Care*, stated that the incidence in Britain ‘*had risen faster than any of the top ten cancers*’ over the last 25 years, and ‘*is forecast to increase by over 50% by 2030, which is the biggest projected increase of any form of cancer*’. The text is accompanied by a graph in which this rate of age-standardised increase towers scarily over much smaller or declining rates of increase for other cancers. However, the statistic is derived from a paper (Mistry *et al.*, 2011). This paper extrapolated to 2030 in linear fashion from observed increases in the period 1984-2007. It lumped together all cutaneous melanomas, including the most common thin forms which are now classified as stage 1 (histologically atypical but biologically benign), and which may be being detected more frequently, creating the illusion of an epidemic. The analysis ignores the relatively low incidences found in higher latitude countries such as the UKⁱⁱ. Such representations direct clinical attention away from uncertainties acknowledged elsewhere in the research literature and drive a sense of urgency, both societal and personal, about the ticking of a metaphorical melanoma alarm clock.

Identified melanoma risk factors include, *inter alia*, sun sensitivity, a tendency to burn rather than tan, cumulative intermittent high intensity exposure particularly in childhood and unaccustomed exposure at any age (Bataille and de Vries, 2008). Ultraviolet radiation is the ‘*common denominator in most melanoma cases*’ (Driscoll and Erickson 2009, p. 285), although a temporal pattern of exposure variation leading to sun-burn, rather than total lifetime ultraviolet radiation dose may be the crucial risk factor (+- *et al.*, 2005)ⁱⁱⁱ. However, the predictive power of ultraviolet radiation exposure as a risk factor

for melanoma should not be exaggerated. An odds ratio of 1.7 has been estimated from a pooled analysis of studies undertaken across global latitudes for greater recreational sun exposure in relation to melanoma of the trunk and legs, the most powerful effect (Chang *et al.*, 2009). A similar odds ratio has been derived from a systematic review of studies of sunbed use before the age of 35 (Green *et al.*, 2007). This odds ratio would mean that, in the UK for example, where the estimated lifetime risk of developing a melanoma is currently about 2 per cent, 2.5% of individuals with a history of recreational sun exposure, for instance from holidays in lower latitudes or from sunbed use, will develop a melanoma at some time in their life, compared with 1.5 per cent of those who had not been exposed in this way^{iv}. Well-intentioned health promotion advice advising members of the public to limit UVR exposure may inadvertently convey the impression that its impact is much greater than these statistics imply, thereby creating a false sense of security for individuals who consider that they had not been unduly exposed, as our data will illustrate. Moreover, the efficacy of reducing population exposure to the sun through public education campaigns, which originated in Australia, has not been demonstrated (Whiteman *et al.*, 2008). Statements about the benefits of sunshine for vitamin D levels^v (Marsden *et al.*, 2010) and notions about the outdoors as healthy, documented in the following data analysis, may cause further confusion about the status of a risk factor, the predictive power of which has been overstated.

With respect to secondary prevention, it is widely assumed that survival chances depend upon the speed with which medical intervention, primarily surgical removal, is undertaken. However, direct evidence for the efficacy of this long-established procedure is lacking (Berwick and Wiggins, 2006). Randomised controlled trials

involving no treatment or placebo surgery controls cannot be carried out for obvious ethical reasons. Mortality risk, often operationalised as five-year survival, is associated with lesion development, measured in various ways, including extent of skin penetration (Clark criteria), thickness (Breslow criteria), degree of ulceration and spread to other parts of the body such as the lymph nodes. The presumed urgency of seeking treatment arises from the belief that surgical removal reduces the risk of lesions progressing to more advanced stages. Improvements in survival rates provide the best evidence that medical interventions do generate increases in life expectancy. Five-year survival in Scotland for patients diagnosed in 1994-1998 varied from about 95 per cent if the melanoma was <1mm thick to around 50 per cent if it was >4mm; and survival rates had increased progressively since 1978-1982 when approximately 35 per cent of those in the latter category had survived for at least five years (Mackey *et al.*, 2007).

Temporal urgency about responding to melanoma is driven by the belief that untreated lesions are likely to grow and become more dangerous over time. However, some disappear, or decrease in size, without treatment (Prestwich *et al.* 2008), and it cannot be assumed that thin melanomas are necessarily younger versions of life-threatening ones (Coory *et al.*, 2006). Surgical excision of those that are detected ensures that their evolution cannot be observed prospectively, an example of the 'inductive prevention paradox' (Heyman *et al.*, 2010, pp. 103-105). Studies of how melanomas develop over time have to rely on patients' retrospective, remembered accounts of when they first noticed a mole. Surprisingly, such studies overall have not found clear evidence that lesions which patients report having lived with for longer are, on average thicker (Baade

et al., 2006) although, more recently, such a relationship has been found (Tejera-Vaquerizo *et al.*, 2010).

Baade *et al.* in the largest study of its kind did find a correlation between time since first detection and lesion thickness, but only for those first detected by a physician rather than a patient in relation to one subtype, nodular melanomas which have an unusually regular structure. They offer a number of explanations for their finding that time-lapse since first patient recognition is not associated more definitively to lesion thickness. They note that backward-looking accounts can only uncover the time period between a patient or health professional first noticing a suspicious lesion (T_1) and seeking medical assessment (T_2), whereas the time between the melanoma starting to develop and being first noticed (T_0-T_1) cannot be identified. The most relevant issue in relation to the theme of the present paper involves the possibility of what might be called 'lag-time bias'. Attributes of the fastest-growing forms of melanoma might result in individuals seeking medical advice more quickly. Although merely speculative, this explanation illustrates the complexities of mapping melanoma risk against time.

Melanoma self-surveillance and treatment 'delay'

Public education to promote early melanoma detection and rapid referral to specialist services are the mainstays of melanoma secondary prevention in the UK and elsewhere, as neither mass nor high risk screening are considered cost-effective (NICE, 2011). The public health advice currently given is that individuals should monitor their own skin in order to identify unusual moles requiring further, medical

examination. Educational materials designed to facilitate accurate self-monitoring use an ABCDE mnemonic to guide identification. The mnemonic refers to mole **a**symmetry, **b**order irregularity, **c**olour variability, increased **d**iameter and **e**volution (Eagle *et al.*, 2010). However, agreement between lay self-assessments and those of dermatologists tends to be low (Hamidi, Peng and Cockburn, 2010). The median detection sensitivity of 62 per cent estimated by Hamidi *et al.* from seven studies would mean that, even when asked to self-examine, members of the public would miss 48 per cent of the lesions which an expert would consider worth assessing further. Rates of self-detection tend to be lower, delays longer and tumour thickness greater among men (Hajdarevic *et al.*, 2011) and people with lower levels of educational attainment (Richard *et al.*, 2000).

The decision-tree leading to treatment of a melanoma or other skin cancer is rarely considered as an overall system. Self-surveillance, the first step in the most common treatment pathway, may result in a patient initiating contact with a general practitioner who may refer them on to a specialist service such as a coloured pigmentation clinic if in agreement that the patient's suspicion is justified, or undertake a biopsy themselves. If referred, a dermatologist will normally decide whether histological examination of tissue is needed. However, the vast majority of those who are referred to a specialist will receive an all-clear judgement with respect to malignancy. For example, an audit undertaken by Moran *et al.* (2011) showed that one clinic detected only 3 melanomas and 16 basal skin cancers among 483 patients referred to a dermatology clinic over a 9 month period. On the other hand, general practitioners overlook a substantial proportion of malignancies. Pockney *et al.* (2009) found that UK general practitioners who

inspected skin lesions missed a third of skin malignancies including melanomas. Even specialists misclassify a substantial proportion of lesions subjected to subsequent histological analysis as melanoma/non-melanoma (Morton and Mackie, 1998). Morton and Mackie found that the provisional melanoma diagnoses given by registrars with three to five years experience at a dedicated pigmented lesion clinic in Scotland were only 62 per cent accurate. The sheer volume of skin blemishes, mostly harmless, which might merit further attention combined with variability in the appearance of malignant lesions make errors of omission likely. The chance of a malignancy being overlooked will be multiplied at each stage of the referral process. General practitioners can only examine lesions which patients draw to their attention, or which they happen to notice incidentally; and specialists will not be able to assess patients who accept reassurance from their general practitioner. 'Failure' to detect a melanoma will become all too clear with hindsight, triggering a retrospective process of moral accounting (Robertson, 2000).

Although not firmly founded in a clear evidence base, the medically and societally organised belief-system in which an 'epidemic' of melanoma is seen to require regular self-monitoring and life-saving urgent referral of suspicious symptoms generates a time-lag problematic. With respect to melanoma, the time period from suspicion to first contact has been variously estimated as 56 days (Faye, Helsing and Langmark 2000) and 110 days (Brochez *et al*, 2001), depending on how delay is defined. Researchers have developed models designed to explain why patients often do not obtain timely treatment. Over 70 years ago, Pack and Gallo (1938, p. 443) analysed '*culpability for delay*', a linguistic choice which conveys a more overtly judgemental tone than might be

adopted today. Perhaps the most influential approach (Andersen *et al* 1995) sub-divides time to treatment into appraisal, illness, behavioural, scheduling and treatment 'delay' periods, each associated with specific appraisal and decisional processes. Scott *et al.* (2013) have criticised this model for failing to adequately take into account the perspectives of those who subsequently learn that they have developed dangerous or fatal lesions. The issues which they raise include patients initially explaining subsequently identified melanoma symptoms in other ways, attempting to self-manage and responding to emotions. Another issue which will be documented in the data analysis below is the cultural context of symptom recognition, particularly appraisal of the social consequences (Andersen *et al.*, 2010).

Given the relative paucity of information on the ways in which patients make sense of and respond to possible melanomas (Nyawata and Topping, 2006), we draw on data from a grounded theory study in order to examine the pre-diagnostic journeys of people living with melanoma from their retrospective perspectives, focussing particularly on temporal issues.

Methodology

In this article we draw on data from a study designed to explore the meaning of shorter and longer time-lapses between detecting signs of what later turned out to be melanoma and receiving treatment to people treated for melanoma. A grounded theory methodology (Strauss and Corbin 1990; Charmaz 2006) was chosen in order to maximise researcher sensitivity to the perspectives of study participants. The open

quasi-inductive approach engendered by theoretical sampling was particularly appropriate for a topic which has received little qualitative research attention. It enabled careful attention to be given to patients' own accounts of their reasons for not responding to what turned out to be signs of melanoma as quickly as they might have done. The analysis focussed particularly on relationships between research participants' risk constructions and their sense of urgency about medical referral.

Ethical approval was granted by an NHS Local Ethics Approval Committee (REC Reference 05/Q1202/114) for the research to be undertaken at an NHS Trust in Northern England where the sub-regional skin cancer centre from which the participants were recruited is located. To protect confidentiality, research participant names have been replaced by pseudonyms.

The main study sample (N=39) was of patients with diagnosed cutaneous malignant melanoma 0.76mm or thicker, and attending a clinic at the NHS Trust to which access had been granted. Lesion thickness was measured on the Breslow scale, which indicates the total vertical height of melanoma cells from the surface (granular level) to deepest point of invasion. Breslow measurements do not take into account ulceration or spread, but are often used in clinical practice because of their simplicity and predictive power for survival prospects (Balch *et al.*, 2001). The purpose of sampling was to access individuals whose melanoma currently posed a serious risk to their health, and who could give accounts of their journeys from first noticing a mole which subsequently turned out to be a melanoma. These research participants offered variable accounts about time-lapses between first noticing a mole and diagnosis of at

least 3 months. In order to maximise variation (Kuzel, 1992) a small sample of individuals (N=6) whose melanoma was less than 0.76mm thick were subsequently recruited. Their responses document a sense of urgency about responding to suspicious moles. Overall, 45 individuals, 24 male and 21 female, aged 21-85, all fair skinned, with blue or green eyes and blond or auburn hair, physical characteristics associated with melanoma, were interviewed. Patients were recruited in three ways. Some were identified by Trust staff from an electronic database and invited to contact the fieldworker, Idah Nkosana-Nyawata, if they wished to discuss possible participation in the study. Some were asked directly by their consultant dermatologist or clinical nurse specialist if they wished to discuss participation. And some gave verbal permission at the outpatient clinic for the field worker to re-approach them a week later. Basic statistical data about time between the lesion being first detected and medical referral, melanoma thickness and their relationship will be presented in the Findings section, below.

The fieldworker conducted interviews which lasted for about an hour and were audio-recorded with consent over a fifteen-month period. The interview topic guide covered five main areas: demographic information; the journey to presentation; reflections on action, inaction and risk over the timeline to presentation; lifestyle and melanoma risk; and learning from the experience. In practice, an approach was adopted whereby participants were invited to tell their stories and probes were used to ensure coverage of the schedule and interrogate emergent themes. Data collection was interspersed with analysis. Thirty-four interviews were conducted in interviewees' homes, eight in a quiet room on hospital premises, and three at informants' workplaces. As will be seen in

the Findings section, the interviews focused mainly on the period in participants' melanoma journey from first noticing the lesion up to the point of diagnosis.

Interviews were transcribed verbatim and analysed with *NVivo*. Each presentation journey was mapped against the five stages of the Andersen *et al.* (1995) model. Line-by-line first-level coding involved making comparisons between transcripts, searching for similarities and differences, and labelling similar phenomena as open codes. Second-level coding generated possible explanations for connections between open codes and reassembled them into 'tentative themes' to form more precise and complete descriptions of the phenomena (Charmaz 2006). The main theme, time-framing, explored in the Findings section is an extension to that original analysis and foregrounds temporal issues. Detection of possible melanoma signs could trigger responses driven by a sense of urgency at one pole or much more sluggish responses at the other, depending upon the person's sense of themselves as at risk and their other priorities. On occasion, a doctor could slow down the individual's metaphorical melanoma clock, with potentially disastrous consequences.

Findings

Time-lapses

Study participants (N=36^{vi}) with more advanced melanomas reported a mean time-lapse of 13 months between initial patient identification of a potential problem and expert confirmation (N=36, range 2-25 months, standard deviation 6.2 months).

The mean thickness of their melanoma at the time of diagnosis was 3.6mm (N=39,

range 1-11.5mm, standard deviation 0.4mm). Respondents with thin melanomas reported a shorter time mean time lapse of about three weeks (N=6, range 0-1.5 months) and the mean thickness of their lesions was 0.5mm (N=6, range 0.2-.7mm).

For the full sample, a statistically significant correlation of 0.42 ($P=.005$, $N=42$) was found between reported time-lapse from first detection and lesion thickness.

However, within the group with more advanced melanomas, the obtained correlation of 0.25 ($P=.2$, $N=36$) between time-lapse and melanoma thickness was not statistically significant. A similar weak, not-significant correlation, of .24 ($P=.3$, $N=6$) was found within the thin melanoma group. These findings can only be taken as evidence for the urgency of excising thin localised lesions as quickly as possible, if it is assumed that thin lesions would otherwise develop into thicker ones, as we have already discussed.

In the remainder of this section, we will examine participants' retrospective accounts of time issues relating to their melanoma diagnosis. We will start with responses given by participants who had engaged quickly with the healthcare system and conveyed a sense of urgency in their response to possible signs of melanoma. We will then contrast their sense of urgency to the temporal attitudes of research participants who had reacted more slowly and were currently living with a dangerous or inoperable condition. We will consider three aspects of their narratives; the way, for a long period of time, they did not see themselves at risk of malignant; the impact of general practitioners who did not recognise the risk of

melanoma providing a false sense of security; and the need to balance the time demands of seeking diagnosis against other critical life issues.

Participants who responded rapidly

The research participants who had decided to go to the doctor soon after they noticed signs of possible skin cancer said that they had done so on their own initiative or because someone close to them had encouraged them to take speedy action. Lulu, after described how, after noticing a qualitative difference between her melanoma and other moles, she had immediately approached her general practitioner.

When I noticed it [a reddish border around an existing mole] I immediately rang my GP, and made an appointment for the next day. (Lulu, 55-64, melanoma on head, 0.2mm, no referral delay)

Lulu's account indicated that she had responded rapidly to the temporal imperative which she and the medical system saw the deviant mole as carrying. Amy reported a similar reaction which she explained in terms of her status as a healthcare worker.

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

then you have to go don't you? (Amy, 35-44, melanoma on leg, 0.6mm, 2 weeks from first observation to general practitioner referral)

As with Lulu, Amy's narrative conveys instant recognition of a serious health problem, although she reported that she only noticed the mole when it was pointed out to her in a social situation in which normally concealed parts of her body were exposed to others. Her narrative acknowledged a general reluctance to take up her doctor's time, but discounted this as a reason for delaying. Her account indicated generalised concern, '*something the matter*' rather than an imminent danger that might be indicated by pain or bleeding. Both accounts conveyed a brisk response to cancer risk indicators.

In contrast, Colin, the youngest research participant in our study, said he had visited the doctor only because his mother had pushed him into it.

Coming back from Spain, I'm nice and well brown, and really pleased, and I'm helping my father in the garden when my mum comes out and says, 'What's that on your back?'. I think it's, like, nothing, but for, like, the next week she keeps on at me, and even makes an appointment at the doctors for me. 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. (Colin, early 20s, melanoma on back, 0.4mm, 1 week from first observation to general practitioner referral)

Colin's account indicated that he had positively valued the tanned brown skin which he had acquired in Spain, and had not seen himself as at risk of skin cancer even when his mother pointed out a mole on his back. She had taken the decision to seek medical appraisal for him. In his account Colin presented himself as having been saved due to his mother's vigilance. He took it for granted that the categorisation of his lesion as 'cancer' legitimated her urgency.

Slower referral

The accounts given above convey a strong sense of urgency, either on their own part or driven by somebody close to them. Research participants reported how the perception that they were at risk of a dreaded condition, cancer, evoked a rapid response. In this section we will examine contrasting accounts from participants whose accounts indicated that they had not referred themselves for a considerable time after noticing signs subsequently indicative of melanoma. They accounted for such time-lapses in diverse ways. Most of their accounts indicated that the 'phenomenological clock' did not start ticking for some time because they did not see changes to their skin as indicating cancer risk. A few participants reported that they had identified a skin cancer risk but did not get to see a skin specialist either because their general practitioner mistakenly rejected the possibility of malignancy, or because they had not gone to their general practitioner in the first place, prioritising other pressing life concerns.

'Delay' in first referral

Unless a health professional happens to notice a possible skin malignancy, speedy diagnosis and treatment depends upon patients referring themselves promptly.

With the benefit of hindsight, it is easy to point to 'delay' and to conclude that if only a patient had taken precautionary steps more quickly, their lives might have been saved. However, most participants in our study indicated that they had not postponed taking action. Instead, they described how they had normalised their symptoms in various ways, as particularly well-illustrated in the following example.

Mathew: 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 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 can't 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 noticed it before.

Interviewer: So what happened next?

Mathew: Well nothing really. It was fine. It was just a red edge on it. I suppose it was a bit raised, come 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.

Interviewer: You seem to be quite relaxed about it, so what changed? What made you go to the GP?

Mathew: It started bleeding. Not lots of blood mind, but all the time like. It got to a point where there was 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 was getting tired of washing blood stains off the sheets and my shirts. (Mathew, 65-74, melanoma on back, 1.0mm, 10.5 months from first observation to general practitioner referral)

Despite hearing about skin cancer risk through the media, Mathew had not gone to his doctor until the mole in question had been bleeding for some time, and then only because his wife had 'sent' him. As also found in other accounts, he had not operated a precautionary principle, but had waited until he was sure that something was 'definitely wrong'. He appeared to discount signs that he was at risk of melanoma, 'letting be' the mole because it didn't itch, and only responded to a symptom, bleeding. Crucially, he had performed his own risk analysis, concluding that because his body had not been exposed to the sun, except during the 1939-1945 war, his mole could not be malignant. This way of thinking overstates the predictive power of variations in UV exposure, and illustrates the difficulty which some respondents had about linking their present condition to risk factors encountered in their distant past.

Kiki's account showed, similarly, how she had located herself in a low risk category, by viewing changes in one of her moles as a normal sign of ageing:

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, when this mole I had had for about ..., 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!' (Kiki, 55-64, melanoma on leg, 3.1mm, 13 months from initial observation to general practitioner referral)

Kiki, perhaps with satirical intent, reported detecting a sudden qualitative shift towards minor ailments which started suddenly on her 50th birthday. Although not necessarily intended to be taken literally, this account indicates that she had seen her mole as a normal consequences of ageing, and, crucially, had not shifted this view when it started growing, eventually to a dangerous thickness. Frank's account was based on the opposite logic, that he was too young to have melanoma

Okay, I knew about melanoma. But I was only 43, and 43 year olds don't get melanoma [laughs], or so I thought. (Frank, 35-44, melanoma on arm, 2.6mm, 7 months from first observation to general practitioner referral)

Although epidemiologically unsound, Frank's statement that he was too young to develop cancer, abandoned with the benefit of hindsight, had contributed to the slowness of his response to potentially suspicious symptoms. He described how he had observed a mole on his arm changing in appearance over a ten months period, but did not do anything because he 'knew' it was not skin cancer. He had

concluded that because his grandmother had developed melanoma in her 80s, it must therefore be a condition of old age.

Bob's account indicated that he required a high threshold of evidence before he was willing to take action^{vii}:

That's how I put all aspects of life that it's 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. (Bob, 55-64, melanoma, 11.5mm, 2 years from first observation to general practitioner referral)

Bob indicated that he had refused to respond to signs that his mole might be problematic despite repeated calls from his wife and daughter to seek medical advice. His mole was only identified as potentially cancerous when he visited his general practitioner for an unrelated health problem by which time the melanoma was untreatable and he died shortly after the interview. Some participants said that they had discounted possible risk of melanoma because they did not see themselves as having any risk factors. Kiki described how she had relied on her 'religious' conformity to health promotion advice.

Well I use sunscreen religiously so I could not imagine that this [melanoma] could be a problem. (Kiki, 55-64, melanoma on leg, 3.1mm, 13 months from first observation to general practitioner referral)

It is possible that the use of sun creams may reduce relative melanoma risk, however this is not proven (see Goldenhersh and Koslowsky, 2011). Kiki's account indicated that as she followed medically recommended practice she had a false sense of security. Her reference to religion suggests that such compliance may carry a function of ritual reassurance which can go disastrously wrong. Similarly, several respondents including Paul depicted the healthiness of outdoor activities.

Paul: Trying to do my bit for the environment I guess, so I walked there [general practitioner surgery]. When I don't cycle I walk you see.

Interviewer: You walk and cycle?

Paul: Mmm. We do quite a bit of walking, as much as we can, or go on our bikes ... I cycle from job to job, get my vitamin D that way [from natural sunlight]. (Paul, 35-44, melanoma on head, 2.4mm, 9 months from first observation to general practitioner referral)

Paul's account of the healthiness and environmental soundness of exercising outside suggests that he may have felt that he was not at risk of developing melanoma, even though these recommended activities would have increased his ultraviolet radiation exposure. In partial contrast, Hugh identified childhood sun exposure as a risk factor, but only in retrospect.

I honestly cannot tell you how many times I burnt as a child. I was always burning, always bright red. I now understand from [skin cancer clinical nurse

specialist] that 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, 45-54, melanoma on back, 2.77mm, 22 months from first observation to general practitioner referral)

Hugh justified his parents exposing him to risk factors in terms of a historical change, stating that "*in those days* [his childhood], *it didn't really matter*". Such shifts preclude responsible risk management since the belief system which could have guided safer behaviour was unavailable at the time when risks were taken. Despite accepting his own impending mortality, Hugh referred only jokingly to 'suing his parents'. His account conveyed the difficulty which he, and no doubt others, felt about linking childhood events to risks faced decades later.

Exceptionally, Samantha recounted responding slowly to signs of possible cancer despite having at the time flagged up multiple risk factors.

My father died of cancer, and my mum died of a brain tumour. My aunt had cancer ... removed from her throat and there is quite a history in my family. And I have always joked I would die of cancer. However, at the time I just thought it 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, at the age of 15 to about 30, I used to go on the sunbeds quite a lot, and there was a big thing about sunbeds. 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! (Samantha, 25-34, melanoma on thigh, 2.6mm, 12 months from first observation to general practitioner referral)

Although contemporaneously identifying two separate risk factors, family history and use of sunbeds, Samantha did not experience alarm about her condition which remained in the '*back of my mind*'. This relatively sluggish time-framing contrasted strikingly with the sense of urgency conveyed in the opening quotations. Perhaps reluctant to confront serious health contingencies, Samantha was metaphorically prodded into action from the grave by her deceased ancestors.

Healthcare 'delay'

Three participants in our study identified time gaps between first referring themselves to a general practitioner and diagnostic tests being provided. Jane, a health worker, felt that her doctor had actively blocked her seeking further investigation, delaying intervention for what might have been a life-critical time period after she had responded fairly promptly to signs that she might be at risk.

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 general practitioner who told me I was fussing unnecessarily. But I said to him I thought they were malignant. But he wouldn't have it. And they, he, made me feel such a fool. I did, I did nothing

about it for a year after that. (Jane 55-64, melanoma on leg, 6.6mm, 2 months from first observation to general practitioner referral)

In terms of the ABCDE mnemonic outlined in the Introduction, Jane had identified at least four changes indicative of possible cancer - asymmetry, border, diameter and evolution. Despite feeling concerned about a possible malignancy, and being a health service insider, Jane had accepted the general practitioner's judgement that she was not at risk.

Dave suggested that his general practitioner had slowed the perceived cancer clock by conveying that there was no urgency about taking further steps.

But she [GP] 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 ...' So I didn't get it done. (Dave, 65-74, 9.9mm, melanoma on back, 9.9mm, 12 months to first general practitioner referral)

He had concluded from the initial consultation that there was no urgency about further investigation, an inference which was confirmed for him by being offered a 'choice' about whether to ask for his mole to be tested. The doctor's reported evocation of 'procedure' conveyed a sense that by leaving it up to the patient to decide, she was following a specified well-founded standard. Dave said that he had returned to the general practitioner 16 months after his initial consultation when his mole had started to bleed, and had grown to a very advanced stage.

Nancy, the third respondent who reported doctor-induced delay resolutely rebutted potential criticism of her GP.

To be truthful, it's alright to be all righteous indignation now. But to be fair to him [general practitioner], I think ... it's the way I told him about the mole. I was more concerned about the stomach cramps ... It was only when he had given me the prescription, and I was at the door, when I remembered and kind of mentioned it. He came to the door and sort of peered at it, but it was kind of awkward considering that I had one hand on the door and the other outstretched for his inspection. (Nancy, 25-34, melanoma on arm, 2.3mm, 17 months from first observation to general practitioner referral)

Patients often mention incidentally symptoms which worry them but which they fear will be considered trivial, smuggling their concerns in with accounts of issues which they feel to be more legitimate. Doctors, perhaps faced with a queue of other patients, might miss such casually presented accounts. It must be born in mind that most mole referrals are false alarms, a situation which engenders false negatives. The consequence of presenting a worry incidentally might be greater delay in obtaining diagnosis than would have happened if the patient had expressed their concern more forcibly.

Multiple concerns and multiple clocks A few of the participants in our study reported that they had identified signs of risk to their own health but had prioritised

other issues which they saw as more pressing at the time. Julie described how she was more worried about her partner who had been recently diagnosed with Type 2 diabetes than with her own prospects.

Julie: I know I sound like a bit of a martyr but he [partner] needed me at the time. I didn't want to upstage him as in who was 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.

Interviewer: 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. (Julie, 45-54, melanoma on leg, 2.0mm, 6 months delay from first observation to general practitioner referral)

Julie indicated that she had at least suspected that the growth on her leg might be a malignant melanoma, but had judged her partner's condition more urgent. She had judged that treatment '*would keep*', that a modest postponement would still allow successful treatment to be implemented. Peter also described delaying taking action, but for a longer period, on account of dealing with concerns which he considered more pressing, including his work, other issues with his own health, and the serious illness of his wife.

Peter: I could feel it [mole]. Yes, when you've got one, and they're a bit thick, you know, and it's a bit rough ... Mind you, I didn't know about all this

business [melanoma diagnosis] ... And then it'd be 12 months ago. Twelve 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 ... It was bleeding, and my wife was dressing it ... We were dressing it but the bleeding never stopped.

Interviewer: And how long did your wife dress it?

Peter: It must have been three or four months. She said it were like a little mushroom thing. 'Go down the clinic', she said, 'They'll cut it off. They have a little surgery down at the Doctor's'. But then she got worse, much worse, and I had to take more time off work, you know. (Peter, 55-64, melanoma on back, 9.6mm, 16 months from first observation to general practitioner referral)

Peter indicated that he had waited a further three months after his wife had encouraged him to go to his general practitioner before making an appointment. Possibly, his wife's use of diminutive language, as reproduced by the respondent, had reassured him that his condition did not require an urgent response. His initial perception, as recounted later, was of a mole which might be problematic rather than of a possible melanoma. But the main factor leading to him postponing referral was the time demands of other concerns, including his work and his wife's deteriorating condition. He died four months after being interviewed.

Discussion

The backdrop to the temporal risk management issues considered in this paper is a prevailing clinical orthodoxy founded on two interlocking beliefs: that an avoidable epidemic of malignant melanoma is occurring as a result of lifestyle choices resulting in high ultraviolet radiation exposure; and that mortality can be largely avoided by self-monitoring followed by speedy self-referral into the healthcare system when signs of skin cancer risk are identified. Health policy documents across the developed world represent cancer as a dread but partly avoidable contingency, the risk of which can be reduced by individuals through managing exposure to risk factors, including ultraviolet radiation, responsibly (Hooker, Carter and Davey, 2009, p. 552). This risk-framing of cancer constitutes individuals politically as '*autonomous, responsible entrepreneurial subjects*' (Robertson, 2000, p. 219).

However, the epidemiological literature reviewed in the Introduction conveys far more uncertainty about these propositions than is sometimes communicated in clinically focused documents such as the report of the UK Melanoma Taskforce (2012). The occurrence of an epidemic and the extent to which the most common thin, localised melanomas evolve into more risky forms both remain unclear. Speedy excision of melanomas which have been diagnosed means that researchers and clinicians can only observe static snapshots of single lesions of different sizes. Their growth cannot be observed directly, but merely extrapolated from these static views. The resulting composite may be compared metaphorically to that of a motion picture in which a series of still images shown rapidly convey a sense of movement through time. Although the representation of a progression in

which a cancerous lesion grows rapidly is not imposed directly by the brain, but is generated from a conscious belief system, the impression of an arrow of time pressing relentlessly forward is comparable. In the case of malignant melanoma, the resulting constructed urgent risk management dynamic is not so much mistaken as subject to under-acknowledged uncertainty.

The strength of the relationship between melanoma risk and sun/sunbed exposure has sometimes been exaggerated in the health promotion literature, as has the ease with which melanomas can be detected even by general practitioners and dermatologists. Counterbalancing health gains may result from sunlight leading to increased Vitamin 'D' levels for people living at high latitudes. The gains in terms of reduced mortality risk of earlier intervention for patients with melanomas at different stages of thickness and penetration have not been firmly established; and 'gold standard' randomised controlled trials with a group in which lesions are not excised cannot be carried out for ethical reasons.

The prevailing ethos for patients who enter the healthcare system with melanomas does not reflect these uncertainties. It is one in which a long-term 'failure' to protect themselves, or be protected by parents, from ultraviolet radiation gives rise to a risky condition requiring them to undertake urgent evasive action. Those who present themselves with more advanced melanomas may be considered to be responsible for a double risk management failure since they have not only exposed themselves or been exposed to primary risk factors, but also have 'allowed' their lesion to grow to dangerous proportions. Although not underpinned by sound

evidence, this risk picture was fully accepted by research participants who were looking back at events preceding their acquisition of a melanoma. Thus, the starting point for framing previous risk management was the taken-for-granted acceptance of a medically 'encoded' but problematic set of beliefs (Alaszewski, 2010, p. 134) about time and risk. At the clinical sharp end of expert summaries (The Melanoma Taskforce, 2012) and clinical guidelines (Marsden *et al.*, 2010), uncertainties tend to be bracketed out, with doubts tacitly suppressed through an unspoken collective process of deletion (Law, 1996). Hence, practice is predicated on acceptance of a package of prevailing risk wisdom as 'scientifically' proven. Ironically, some participants accounts suggested that exaggeration of the benefits of following health promotion recommendations had slowed down their response to possible symptoms of melanoma as they had judged themselves to be not at risk because they used sun blocks or followed a healthy lifestyle. Two research participant, Mathew and Bob, with had (mis)applied the principle of scientific evidence, reasoning that he should not seek advice unless he had clear evidence that he was facing a health problem.

A cancer diagnosis fixes a time-point in a personal biography triggering a fateful moment (Scammell and Alaszewski, 2012) and shifts the largely unconsciously experienced taken-for-granted body to the foreground (Timmermans and Buchbinder 2011). It differentiates the healthy body from a component which has come to be viewed as diseased, and as therefore requiring expert surveillance and intervention. For participants in our study, especially those who delayed seeking expert advice, what turned out to be symptoms of cancer had belonged previously

to everyday existence, easily normalised and explained away. Research participants who now knew that they had developed malignant melanoma used this framework to relate biographically historic events such as having been sunburnt, to their present health problem. This personal auditing and accountability setting can be put into perspective in relation to the low relative and absolute risk increase statistics presented in the Introduction. Our research participants, lacking access to the critical literature, took the over-confident explanatory claims of encoded medicine at face value.

Participants explained their management of time in response to what turned out to be symptoms of a potentially deadly cancer in diverse ways. Those in the 'rapid response' group who had presented with thin, localised, lower risk lesions generally conveyed the sense of urgency expected of good citizens living in a risk society, which they had responded to either directly or through the agency of family members. Although it is tempting to conclude that they saved their lives by responding to risk indicators in this way, the research evidence does not yet firmly support this view, as already noted. Counterfactually, their melanomas might have disappeared unnoticed if they had not been diagnosed and excised. There is still uncertainty even about the existence of a relationship between time to diagnosis since a suspicious sign was first noticed and lesion thickness (Baade *et al.*, 2006).

The retrospective narratives offered by research participants who had developed more advanced melanomas all acknowledged time-lapses between first noticing a bodily change and seeking medical appraisal. Their accounts of their decision-

timing revolved around one or more of three main features: firstly, normalising mole appearance, for instance as a minor consequence of ageing; secondly, having been reassured by their GP, falsely with hindsight, that their lesion was harmless; and, thirdly, prioritising other life issues such as the serious illness of a family member as more pressing. Only the third type of account involved intentional delay. The first two categories involved classification errors, but distinguishing correctly between harmless moles and those worthy of further investigation prospectively may be much harder than it appears with hindsight. Patients who now know that they are living with a dangerous or terminal cancer may underestimate the signal detection challenge which they and/or their doctors had previously faced. As argued by Scott (2013) those who normalise signs which turn out to be melanoma symptoms, or accept medical reassurance, do not 'delay' treatment-seeking because they did not contemporaneously see themselves as being at risk. Perhaps more uncommonly, individuals who subsequently learn that they have developed a dangerous melanoma may delay going to the doctor because they prioritise more pressing concerns such as caring for a sick relative, thereby intentionally taking a risk which, with the benefit of hindsight, they may regret.

The subsequent moral position in risk society of those who have 'failed' to activate secondary prevention for melanoma may be compared with that of social workers who have missed a child protection case (Kearney, 2013). In both cases, the hindsight effect can make it difficult to visualise the risk picture as it would have appeared before a highly adverse event occurred, retrospectively splitting previous

signs of a possible problem from the vast majority which were not. Despite living with a dangerous or terminal malignancy which might have been detected earlier and cured, research participants could express remarkably philosophical and humorous attitudes about their predicament, at least in interviews. Hugh laughingly talked about *'the possibility of suing my parents for negligence'*. Samantha said that dead relatives who had succumbed to cancer had *'made'* her go for treatment, albeit 12 months after she had first noticed a lesion. It may be that contemplation of their own mortality in relation to time-scales encompassing generations can engender more reflective views about the human predicament than are envisaged in the prevailing preventative culture of risk society.

Conclusion

A standard public health position conveys a risk picture in which the threat to health arising from an epidemic of malignant melanoma can be managed through citizens managing their personal risk responsibly. This cultural script enjoins the public to undertake primary prevention by moderating their exposure to ultraviolet radiation; and to carry out secondary prevention by self-monitoring for, and responding quickly to, suspicious signs. This risk picture is not so much false as riddled with under-acknowledged uncertainties about the impact of personal exposure to ultraviolet radiation, the occurrence of an 'epidemic', the predictive utility of self-monitoring and the efficacy of medical interventions at different disease stages. However, everyday clinical and personal practice is predicated on

leaving these uncertainties unacknowledged, so that the starting point for risk management is treated as if it were beyond doubt.

Detailed qualitative research can contribute to understanding how members of the public interpret and respond to signs which might indicate cancer. As illustrated in the data analysis, some individuals feel a sense of urgency when they detect bodily signs which raise their suspicions and receive prompt treatment, the personal efficacy of which can never be known because their untreated trajectory becomes counter-factual. Others lived with what turned out to be melanoma for many months, mostly not because they intentionally 'delayed', but because they normalised lesions or were given the all-clear, mistakenly with hindsight, by their general practitioner. For them, the melanoma clock did not start to run until, perhaps too late, although, again, their outcome if they had received speedier treatment becomes unknowable. Of particular interest both practically and theoretically is the false reassurance which some patients had derived from health promotion messages, reasoning that if they used sun blocks, avoided excessive exposure to the sun, or even maintained a generally healthy lifestyle, they could not possibly have developed malignant melanoma. Although involving a misunderstanding of risk-thinking which can only provide knowledge about degrees of uncertainty, this paradoxical unintended consequence of health messaging merits further consideration.

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ⁱ The thinning of the ozone layer is rarely mentioned as a risk factor for malignant melanoma, despite evidence of its significance (Diepgen and Mahler, 2002).

ⁱⁱ The privileging of relative risk over absolute risk increase, sometimes reinforced by graphical icon, provides a means of emphasising the importance of managing a risk factor which misleads for uncommon adverse events (Gigerenzer, 2002, p. 34), most notoriously in relation to the contraceptive pill scare of 1995 (Barnett and Breakwell, 2003).

ⁱⁱⁱ Gandini *et al.* (2005) concluded from their systematic review of research evidence that high, steady exposure to UVR is, statistically, an apparently **protective** factor for malignant melanoma risk. However, they argued that this finding results from the low exposure group including more individuals who have been exposed sporadically to, for them, unusually high doses of UVR from the sun. However, ironically vitamin 'D', mostly obtained from sunlight, may reduce melanoma risk (Egan, 2009).

^{iv} More impressive relative risk statistics might be obtained for greater contrasts between the higher and lower risk categories, for instance between individuals with histories of severe childhood sun-burn and 'the rest'. As always, the size of odds-ratios may depend upon how a comparison is specified.

^v Ironically, given that sunlight is an important source of Vitamin D, reduced levels have been identified as a possible melanoma risk factor (Randerson-Moor *et al.*, 2009).

^{vi} Time lapse could not be ascertained for 3 of the 39 research participants in this sample.

^{vii} Although this research participant had failed to meet the requirement of responsible risk management, his rationale draws on an inherent ambiguity of risk-thinking which oscillates between the precautionary principle and the idea that actions should be evidence-based.