BMJ

BMJ 2012;344:e2319 doi: 10.1136/bmj.e2319 (Published 11 April 2012)

PRACTICE

A PATIENT'S JOURNEY

Superficial spreading melanoma

This patient was diagnosed with superficial spreading melanoma, which had spread to the lymph nodes. Treatment seems to have been successful, but she has been perturbed by some clinicians' reluctance to discuss prognosis

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

"You do understand this is cancer?" asked the dermatologist. It would be another few months before I fully understood the significance of this sentence and its implications. At that precise moment, it was just a mole: asymmetric, with irregular borders, of different colours, bigger than the diameter of a pencil, and elevated. In fact, everything the ABC rules of dermatology said it shouldn't be. My GP had said it would probably be fine, and I could leave it alone. Only it hadn't been fine, and it was lucky I hadn't left it alone. Except that it had been left alone long enough to march unrepentantly to my lymphatics, where it had settled comfortably into my sentinel node.

The dermatologist had just confirmed Google's tentative diagnosis of a superficial spreading melanoma. She mentioned survival rates. What? Along with the rest of the population, I thought that if it was malignant they would cut it out and that would be the end of it. Survival rate? This was a new concept, and one that I hadn't entertained.

My mole had a low mitotic rate (good), minimal inflammation (good), and no ulceration (good). On the other hand, it had a Breslow thickness of 1.8 mm and was Clark level IV, meaning that it was neither early nor thin. It was a mole with a mission. I found it incredible that something so thin—1.8 mm for goodness sake—could kill.

I returned one week after the wide excision and sentinel node biopsy to receive my results. The odds were heavily in my favour, as 80% of patients have no sentinel node involvement. The surgeon rather overplayed the fact that the wide excision was clear, and I could tell by his eager delivery of this result that the next one would be less favourable. I was right; the sentinel node was positive.

I returned for axillary clearance. The "likely" side effect of lymphoedema frightens me more than anything else. Not only cosmetically (who wants to look like the Michelin man?) but also functionally (I am very right hand dominant).

The results were good: 15 nodes removed, none cancerous, stage IIIa regional metastasis. My upper arm and shoulder are numb, but this is a small price to pay. I was elated. I opened a bottle of champagne and got drunk. Then came the questions.

The plastic surgeon told me that the survival rate for people with my condition was above 90%. This couldn't be right. I had understood that it had been above 90% before they knew the cancer had marched triumphantly to the sentinel node and planted its flag. Thankfully, it hadn't started its ascent towards the summit, but was firmly ensconced in base camp at two separate locations.

The dermatologist told me survival was 67% at five years. One in three people would be dead in five years? "If that's the way you want to look at it," she said with exasperation in her voice, which rather suggested she wished I hadn't vocalised this. It wasn't that I wanted to see it that way; rather I couldn't really believe I might be staring my mortality in the face at the age of 41. I don't really believe I will die, because I am only 41 and it's only a mole. Also, I know the dermatologist won't let me die—even though, deep down, I understand that if the scud missile has me on its radar, there is nothing she can do. She explained that they knew there was no cancer where the mole had been (hence the wide excision) nor in the lymph nodes (hence the axillary clearance). What no one knew was whether there were any micrometastases in transit between the mole site and the lymph nodes. This was the piece of information that I lacked.

Perhaps I should have mentioned earlier that I am a "complicated" patient as there are various possibilities as to why I had this melanoma. The commonest cause is sun exposure, but I am definitely not an ardent sun worshipper. It is more

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probably because of the biologicals (biologically derived drugs) I take for my seronegative spondyloarthropathy, which increase the risk of tumour because of their immunosuppressant nature. Or perhaps it's because of family history; my brother had a melanoma. Or perhaps because I lived in west Africa as a baby and toddler in the days before sun cream (but also in the days when we had an ozone layer). Or maybe because I have that pasty Scottish tartan skin which my dermatologist informs me is Fitzpatrick type II. Or maybe a combination of all these factors.

Finally, I had an appointment with the oncologist, who delivered his monologue. Did I wish to go back on the biologicals that everyone seemed to see as the cause of my melanoma? I wasn't sure. My understanding is that melanoma at this stage is sneaky and aggressive and resistant to the usual chemotherapy channels available for other cancers. Treatment is usually adjuvant therapy in the form of interferon or clinical trials (such as bevacizumab). The oncologist concluded that, because I have arthritis and despite the rather disturbing fact that every other patient with stage IIIa melanoma is offered it, I should not be offered adjuvant therapy. He thought interferon would aggravate the arthritis as it stimulates the immune system, and I would not be eligible for the bevacizumab trial because of the arthritis. Did he ask me for my opinion? No, he discharged me and abandoned me to my fate. I left, not understanding the likelihood of recurrence or my chance of survival. I found the door effectively closed in my face with the same recurring thought: melanoma kills, arthritis does not.

To summarise the findings of my mole, my vocabulary now included terms such as superficial spreading melanoma, sentinel node, Breslow thickness, axillary clearance, lymphoedema, micrometastases, and adjuvant therapy, but I still didn't really understand the process of recurrence and survival rates. Not everyone with recurrence dies, right? And you can't die if you have no recurrence (excluding other causes like being hit by a bus), so why did these figures not add up? The oncologist had discharged me, which, to me, rather suggested that I was not worth saving.

I didn't actively seek a second opinion. I merely emailed my rheumatologist to update him. This was normal as my care was confusingly spread over three hospitals. The rheumatologist emailed back immediately saying he thought that I shouldn't automatically be excluded from further treatment because of my arthritis if this is what would normally happen. He then (bless him) referred me to the oncologists at his hospital.

Weeks later, I faced a new oncologist. She disagreed with the previous oncologists and enrolled me in the bevacizumab trial. This is really confusing. Two centres run identical trials, yet I am eligible for one and not the other? The cynic in me wonders if one of these centres is skewing its results. This oncologist didn't dodge my questions but agreed with me that I needed to know the facts so that I could make informed decisions. My feeling was that everybody was expecting the cancer to recur but nobody was saying it. Yes, she said, that is exactly what they were all thinking. With all the other factors (arthritis, family history) thrown in and a "significant chance of recurrence," she gave me a low five year survival probability (50%).

I haven't taken my biologicals for one year now but must decide if I wish to restart them. My rheumatologist informs me that there is "a small but measurable risk" in terms of melanoma. I cannot ignore the fact that I have chronic arthritis and must balance the quality of my life with the risk the biologicals pose. There may be no issue anyway as I may already be cured. I don't know. The excellent team who monitor me so closely don't know. But, I have every confidence that this team will "sherpa" me to the top of the five year mountain, where I will triumphantly plant my very own flag.

Competing interests: All authors declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

Not commissioned; not externally peer reviewed.

Accepted: 25 November 2011

Cite this as: *BMJ* 2012;344:e2319

A doctor's perspective

When Penny first showed me the mole on her abdomen, I experienced that sinking feeling that a dermatologist feels when they are fairly sure that they are staring at a new presentation of a melanoma. I had been suspicious after taking the history: a longstanding mole that had changed shape and colour in a patient with very pale skin. Penny had been born in England but had spent much of her youth in sunny countries. When I asked her if she had ever worn any sun protection as a child, she laughed and said, "We wore nothing." Penny's brother had already been diagnosed with a melanoma. In addition, because of her seronegative spondyloarthritis, she had previously taken several immunosuppressive drugs, some of which are believed to increase the risk of developing cancer.

At this point it is difficult to know whether to be completely open and voice your suspicions or wait until you have histological confirmation. This is where I try to "feel" what the patient wants to know at this stage. I told Penny that the mole needed to be removed and offered to excise it at the end of the clinic. As she agreed straightaway, there was no need to heighten her anxiety by saying that it needed to be removed urgently. Neither of us talked about "melanoma." I removed the mole on her abdomen, giving it a small margin of surrounding normal skin. I noted that she had several other unusual looking moles and wondered if she had the dysplastic naevus syndrome, which increases a person's likelihood of developing melanoma.

The histology report was verified after 10 days and confirmed my clinical suspicion—a superficial spreading malignant melanoma with a Breslow thickness of 1.8 mm. The histology results were reviewed at the local and regional skin multidisciplinary team meeting, and further treatment and investigations were recommended.

I brought Penny back to the clinic and braced myself to give her news that I thought she would not be expecting. Do I just come out with the words "I am sorry but it is skin cancer" or do I work up to it slowly, firing "shots across the bow" as I was taught in my National Communication Course. After one consultation, how can you gauge how best a patient will take bad news?

I always break bad news in the clinics with our skin cancer nurse specialist present, as support for the patient. My previous consultation with Penny suggested that she would rather be told any bad news straight out—I hoped I had judged right.

When I explained the diagnosis to her, she looked almost relieved and said she had suspected that this would be the case. I explained that further surgery would be required to remove some more skin from around the scar, but that we would also recommend her having a sentinel lymph node biopsy from the draining lymph node basin. This staging investigation can be offered to patients who have had a melanoma removed with a Breslow thickness over 1 mm. I dictated a referral to the plastic surgeons who would perform the surgery at the regional skin cancer centre, and arranged to see Penny again after her surgery so that I could continue her skin surveillance and arrange any further investigations. I gave Penny the contact details of our cancer nurse specialist, who was also named as her key worker—the person to contact if she had any worries, fears, or delays in appointments.

I asked Penny if she had any further questions. Very rarely, in all the years that I have been giving bad news regarding skin cancer, has anyone asked me "How long have I got?"

I was relieved when Penny smiled again and said she had no more questions and that we would meet up again after her surgery.

Penny Thomson

Resources for patients and clinicians

- Macmillan Cancer Support (Access link here)—UK charity providing information on malignant melanoma, including how it is diagnosed, possible treatments and side effects, and how to get further support
- Cancer Research UK (Access link here)—UK charity providing information about melanoma, including survival rates and prognosis
- British Association of Dermatologists (Access link here)—Professional organisation providing information and guidelines on "prevention, diagnosis, referral and management" for melanoma
- Goldstein BG, Goldstein AO. Diagnosis and management of malignant melanoma. *American Family Physician* 2001;63:1359-69 (www.aafp.org/afp/2001/0401/p1359.html)—Informative article in a peer reviewed journal
- SkinCancer Net (www.skincarephysicians.com/skincancernet/)—US website from the American Academy of Dermatology. Provides information on melanoma, including staging (/staging.html) and recurrence (/melanoma_returns.html)