Title: Patients' perspectives of long-term follow-up for localised cutaneous melanoma

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Abstract:

Background Little is known about the value of long-term follow-up for localised cutaneous melanoma from the patients' perspective. This study aimed to explore the benefits and potential downsides of follow-up; feelings about changes to frequency of follow-up, and patient-centred recommendations for improving follow-up care.

Methods Qualitative analysis of 29 in-depth interviews conducted with Australian patients undergoing long-term follow-up after surgical treatment of stage I/II melanoma.

Results Patient-perceived benefits of follow-up included reassurance, early detection of new melanomas and non-melanoma skin cancers, education about skin self-examination, the opportunity to ask questions, and reinforcement of 'sunsafe' behaviours. Downsides included anxiety leading up to and during follow-up visits; inconvenience of travel to attend visits; and lost work time. Patients varied in their engagement with skin-self examination, and their views on multiple skin excisions, but highly valued access to specialists for unscheduled visits. Most patients felt their follow-up intervals could be extended to 12 months if recommended by their clinician.

Conclusion The benefits and potential downsides of follow-up should be discussed with patients when deciding on a melanoma follow-up plan to achieve a balance between inducing additional patient anxiety and providing reassurance. Follow-up intervals of 12 months appear to be acceptable to patients.

Introduction

The incidence of cutaneous melanoma in the United Kingdom, the United States and Australia has doubled over the last twenty years, [1-3] however the mortality rate for localised disease remains quite low with five-year relative survival in 2008 reported between 92% and 98%.[2,4] Increased survival and therefore increased prevalence has lead to a rapidly growing number of patients in many countries attending post surgical follow-up. Clinical practice guidelines in the United Kingdom and the United States recommend that patients with American Joint Cancer Committee (AJCC) stage I/II melanoma have intensive follow-up at three to six monthly intervals for the first five years and then yearly thereafter.[5,6] In Australia, life-long follow-up is often recommended but incurs a substantial commitment of time and effort by both patients and physicians.[7]

The main goals of melanoma follow-up are to detect recurrent disease and new primaries, to provide psychosocial support, and to systematically collect data to measure treatment outcomes.[8,9] While there is little good evidence to guide the frequency of melanoma follow-up, a recent analysis by Turner and colleagues suggests that reduced frequency for patients with AJCC stage I or II disease results in only a small difference in the number of patients whose diagnosis was delayed by more than two months, while substantially reducing the number of lifetime follow-up visits required.[10]

Before any changes are made to reduce the frequency of follow-up, it is important to examine the value of follow-up from the patients' perspective, particularly with respect

to the above-mentioned goal of psychosocial support and its role in ongoing melanoma 'survivorship'. Qualitative research methods provide the opportunity to gain an understanding of patients' perceptions and experiences,[12] and are particularly suited to exploring patient-important goals in cancer care. The aims of this study were to; (1) explore patients' perspectives of the value of follow-up care; including its benefits, limitations and potential downsides, (2) examine patients' thoughts and feelings about changes to the frequency of follow-up, and (3) elicit patient-centred recommendations for improving follow-up care.

Patients and methods

We conducted semi-structured in-depth interviews with patients undergoing long term follow-up after surgical treatment of AJCC stage I/II melanoma. Patients were recruited from a single centre, Melanoma Institute Australia.. Participants were selected through a purposive sampling strategy to meet the objective of maximum variation of the sample; that is to represent both stage I and stage II melanoma; to include patients across age groups; to represent follow-up care with different physicians; and to include patients with more recent as well as long-term experience of follow-up**.** Interviews were conducted by four female social scientists, not responsible for the patients' care; either face-to-face or over the phone. The interview guide is summarised in Table 1. Participants provided informed consent and the study was approved by the ethics committee of Sydney South West Area Health Service, protocol #X09-0364.

All interviews were audio-recorded and transcribed. Framework analysis was conducted in two stages following the method outlined by Ritchie.[13] First, a descriptive framework of categories was abstracted from the initial patient interviews by authors RM, LR and KM. The framework categorised key themes related to patients' experiences of follow-up and reported benefitsand downsides. When all relevant concepts were classified and no new issues were being raised in later interviews, further analysis explored the explanations given by patients for their thoughts and feelings, and identified relationships between the descriptive categories. In addition we specifically searched the data on all psychosocial outcomes (cognitive, emotional, social and behavioural) proposed by Bossuyt and McCaffery.[14] To support data management, analytical frameworks were developed in Microsoft Excel.

Results

Thirty patients were interviewed between May and July 2010. One patient was excluded due to subsequent reclassification to stage III disease and thus 29 were included in the analysis. Participant characteristics are listed in Table 2. Interviews occurred in the patient's home, workplace or in the Melanoma Institute on a separate occasion to the follow-up visit. Six interviews were conducted face to face and 23 by telephone. Interviews ranged between 12 minutes and 72 minutes, (mean 30 minutes).

For the study participants, a melanoma follow-up visit consisted of a consultation with a physician for medical history and physical examination, (which included the primary melanoma site, regional and visceral lymph node fields), with or without a full-body skin examination. Diagnostic imaging and skin photography was conducted for some patients at the physicians' discretion.

We describe the study findings below under the following headings: patient-perceived benefits and downsides of follow-up; views about frequency of follow-up and risk perception; views about multiple excisions; involvement in skin self-examination; and patient-centred recommendations for follow-up care. The benefits and downsides of follow-up are summarised in Table 3 and illustrative quotations are included in Table 4..

Perceived benefits of follow-up

Reassurance

The overwhelming benefit to patients was the reassurance they gained from seeing a competent skin specialist whose findings they could trust. This feeling of reassurance

was related to several factors. First, the confirmation of no new melanomas, as patients' main concerns were related to a fear about further disease and they primarily sought confirmation of their hope that they remained disease free. Comprehensive skin checks especially in anatomical locations the patient could not see (such as their back, neck and soles of feet) added to this reassurance..

Second, patients were reassured by the experience of the Melanoma Institute physicians, in particular the reputation of the surgeons and the tertiary referral hospitals. This reassurance was related to the physicians' ability to give definitive answers regarding suspicious lesions, as well as the prompt and appropriate treatment of a suspected new melanoma or recurrence. Third, patients felt reassured by continuity of their follow-up care, particularly when the surgeon who initially treated them provided ongoing follow-up. Patients described feelings of comfort, confidence and security, of being listened to and of being looked after.

Early detection and treatment of other skin cancers

Some patients felt the benefit of follow-up was the earlier detection of a new primary melanoma that was still thin, or had not become too 'advanced'. (Table 4) Many patients agreed that an additional benefit of regular follow-up was the treatment of other non-melanoma skin cancers, . particularly the convenience of having them removed in a single follow-up visit, at the same time as their melanoma skin check.

Education

Gaining knowledge about the diagnosis of melanoma and an explanation of the degrees of severity was another perceived benefit of follow-up. Patients valued the opportunity to learn about their ongoing prognosis and the changing risk of recurrence over time. (Table 4)

Patients also described the benefits of learning about broader topics in melanoma care such as the patterns of genetic inheritance for melanoma, new melanoma treatments such as B-RAF kinase inhibitors, as well as opportunities to participate in research studies. In contrast to the majority of participants who valued follow-up as a source of expanding their knowledge and understanding of melanoma, two patients said they did not want to know anything else about melanoma because talking about the topic was a source of anxiety.

Opportunity to ask questions

A consistently reported benefit of follow-up was the opportunity to ask questions of a melanoma specialist. These included questions about the signs or symptoms patients had experienced in the interval between follow-up visits; individual moles or changes to their skin; the risk of melanoma to their family members; whether there was a need for further investigations (i.e. diagnostic imaging); and questions related to prevention, such as 'how effective are sunscreens?' Patients valued expert opinion, and would often store up a number of questions for each follow-up visit.

Health promotion - sun safe behaviour (self and family)

Patients valued follow-up for its reinforcement of sun safe behaviours and appreciated education about sun protection as an ongoing reminder to themselves and their family. For example encouraging the use of hats, long sleeved shirts and broad spectrum sunscreens, and covering up when outdoors. As a result of these reinforced messages many patients talked about changes to their behaviour to minimise sun exposure.

Perceived downsides of follow-up

Anxiety

Anxiety associated with follow-up visits was an important concern which was experienced by a large proportion of the study participants. Symptoms of this anxiety included insomnia, teeth clenching, apprehension, paranoia, feelings of nervousness and tension, unease, feelings of dread when passing the hospital and ruminating about the worst-case scenario. Patients reported that these symptoms started from one week prior to the visit to approximately one hour beforehand. However all participants stated that they felt relieved once the visit was over, especially when a 'melanoma-free' diagnosis was given. Patients identified a number of different factors as the source of their anxiety. Some were anxious about being told of a recurrent or new melanoma; particularly if they had friends or family members who had died of melanoma (or other cancers), and follow-up visits served to remind them of the severity of the disease. Others were anxious about their follow-up due to a prior bad experience with their initial diagnosis, such as a suspicious lesion that was dismissed as benign. Patients also reported feeling worried and fearful of cancer spreading in their body, and again attending follow-up brought these thoughts to the forefront of their mind.

Inconvenience of travel and lost work opportunity

The distance required to travel to the Melanoma Institute was commonly identified as a downside for attending regular follow-up. Some patients travelled many hours to get to the Institute, but on the whole nearly all patients felt the travel and inconvenience was worth it for the specialist care received. Several patients had tried follow-up at a local skin cancer clinic closer to home and many had returned to the Melanoma Institute, or chosen to alternate their follow-up care with a local primary care physician. Some patients reported that a melanoma follow-up visit meant a full day of work was lost which made it expensive, particularly for those in casual employment who were not eligible for paid sick-leave.

Frequency of follow-up and risk perception

The frequency of recommended follow-up often signalled the level of risk (disease severity) to patients. When the follow-up interval was extended from four to six months, or from six to 12 months, this was generally viewed by patients as a marker of good health. Similarly if the frequency was reduced from 12 monthly back to 6 monthly this was often seen to signal an increased risk of recurrence or a new primary. Across the sample, there was complete trust in the physicians' recommendation about frequency of follow-up, with most patients saying they would accept an increase or decrease as recommended. This was based on the belief that intervals would not be extended unless it was safe to do so. Some patients however said they would be reluctant to extend their intervals beyond 12 months. This was related to past experiences of having to make unscheduled visits for new lesions that appeared between follow-up visits, or a fear that

a new melanoma could grow fast enough to kill if left undetected for more than 12 months.

Views about multiple excisions

Excision of multiple skin lesions was perceived by patients as either a positive or negative practice, depending on the patient's interpretation of why it was being done, or whether they valued a 'conservative' versus 'better safe than sorry' approach to care. For example, multiple excisions were perceived as a positive practice by those who preferred early excision and removal of *any* potentially malignant lesion as quickly as possible. For other patients multiple excisions indicated a physician's lack of confidence in being able to conduct accurate lesion assessment and diagnosis. Many patients expressed concern about the multiple excisions that had been performed at skin cancer clinics and questioned whether the doctors involved might have been motivated by a financial incentive.

Involvement in skin self-examination

Patients varied in their engagement with skin self -examination between follow-up visits. Our sample included some patients (and partners) who were very involved in checking their skin every month. These patients reported that the early detection of melanomas was a shared responsibility between themselves and their doctor. Others were not engaged in self-examination at all and preferred to completely transfer the responsibility for skin checks to the Melanoma Institute physicians.

Recommendations for follow-up care

While most patients were pleased with the follow-up care they received, there were a number of suggestions to make the follow-up more patient-centred. To support their psychological and emotional needs patients suggested longer consultations with their surgeon at the time of initial diagnosis. As follow-up progressed over the longer term some patients felt that other health practitioners such as specialist nurses could support these needs. In addition, peer support programs during follow-up were suggested to help come to terms with being a melanoma survivor. In terms of improvements to the follow-up service, patients suggested a reminder system for scheduled visits and an on-site outlet or shop for purchasing sun protective clothing.

Discussion

This study raises several new findings with implications for melanoma practice related to how patients may interpret key aspects of follow-up care. First, the benefits and potential downsides of follow-up should be discussed with patients when deciding on a cancer follow-up plan, as a balance is required between inducing additional patient anxiety and providing much wanted reassurance. It may be helpful for physicians to inform new patients that others find follow-up visits anxiety provoking, but this is mostly outweighed by the reassurance gained.

Second, the frequency of follow-up signals a specific level of risk to patients. This suggests the importance of discussing with patients the correlation between frequency of follow-up and risk, and the basis for any changes in frequency of visits. It may also be important to differentiate between changes made to the schedule of an individual patient, e.g. due to developments in their personal risk profile, and more general changes recommended in follow-up guidelines. Most patients would be likely to accept follow-up intervals of 12 months if it was recommended by their physician; however they would need assurance that they could make an unscheduled visit at short notice if required. Third, because multiple excisions were viewed both positively and negatively by patients, it may be important for physicians to discuss their approach to suspicious lesions and explore how that corresponds with the patients' own preferences. For example, clarifying whether patients prefer to have lesions biopsied and removed immediately, or alternatively, observed with a careful watch and wait approach.

Finally, there are implications arising from the apparent variation in patients' engagement with skin self-examination. Although a majority of recurrences or new melanomas are reported to be self-detected,[15] patients who are reluctant or unable to engage in skin self-examination may require more frequent follow-up visits than those who take an active role in monitoring their own skin. Patients who are willing to share the responsibility of skin surveillance, and feel competent in their ability to check for recurrences and new primaries, may be more likely to find a suspicious lesion and return earlier for an unscheduled visit with their doctor. These patients may find less frequent follow-up acceptable and their physicians may also feel confident in seeing less often those patients who are fully engaged in self-examination. It is not clear, however, if they are any better at assessing skin lesions than those not engaged in regular self-examination. A training program for motivated patients and their partners could improve the level of self-detection.[16]

This study confirms findings from our previous systematic review of patients' perspectives on melanoma follow-up, that anxiety is common, but that patients highly value the reassurance, information and psychosocial support they receive during follow-up.[11] The patients participating in our study were knowledgeable about melanoma follow-up and satisfied with their care. This differed substantially from the findings of a study of survivors of other tumour types who said they did not know what to expect after active treatment was completed and felt they did not receive adequate follow-up.[18]

If the frequency of scheduled follow-up visits for patients with stage I/II melanoma was reduced then our study suggests the following may need to occur to meet the

psychosocial needs of patients in other ways. (1) A longer consultation following surgical treatment that focuses on the aims and frequency of the follow-up schedule. (2) A clear process for unscheduled visits should the patient and/or their primary care physician be concerned about new disease. (3) A skin self-examination training program for patients and their partners that discusses signs and symptoms of melanoma, and outlines the recommended frequency of skin self-examination.

Limitations

Patients in our study sample were all actively attending follow-up at the Melanoma Institute Australia. Even though some may have missed one or two scheduled visits in the past, they did not represent patients who choose not to participate in follow-up at all, or who may attend local physicians only. Our findings may thus only be transferable to the type of patients who adhere to follow-up schedules in specialist centres.

Further research subsequent to this study could include surgeons' perspectives of melanoma follow-up and the perceived impact of a reduced frequency of follow-up on long term care. Further research related to interventions to improve psychosocial care in melanoma follow-up could be examined. We note that a randomised controlled trial of less frequent follow-up for patients with stage I/II melanoma patients is underway in the Netherlands.[19] with the primary end-point a composite measure of patients' well-being, (expressed in health related quality of life, level of anxiety and satisfaction with the follow-up schedule).

Conclusions

The benefits and potential downsides of follow-up should be discussed with patients when deciding on a melanoma follow-up plan, as there is a delicate balance between inducing patient anxiety and providing much wanted reassurance. Patients could benefit from knowing the rationale for excision of new lesions and the implications of any changes to follow-up schedules. Our study suggests intervals between follow-up visits could be extended to 12 months if patients were confident that they could access a melanoma specialist at short notice.

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Table 1. Summary of semi-structured interview guide*

Experiences of follow-up: positive and negative

1. Tell me a bit about what it is like to come for the follow-up appointments?
2. What are the main things that you get from coming for regular follow-ups?
3. Do you also attend for regular skin checks anywhere else other than the melanoma unit?
4. How do you usually feel about coming to see the doctor?
5. Would you say there are any (other) good things or downsides about coming for regular follow up appointments?

Personnel conducting follow-up

1. How important is it to you what type of health professional does your ongoing skin checks in the future?

Intervals between appointments

1. What about the length of time between appointments – does the gap between visits suit you?
2. Have you ever found any suspicious moles or changes in your skin between appointments?
3. Have you ever missed or rescheduled a follow-up appointment?

Information and other needs

1. What has been the most useful source of information about melanoma?
2. Is there anything else that you would like to see added to the follow-up or monitoring process?

*Full interview schedule available from authors

Table 2 – Patient characteristics (n=29)

Characteristic		**n**	**%**
Age group (years)	20-29	1	3
	30-39	1	3
	40-49	2	7
	50-59	9	31
	60-69	11	38
	70-79	1	3
	≥ 80	4	14
Sex	Male	17	59
	Female	12	41
Highest education level	Degree or higher	11	38
	Diploma or certificate	7	24
	Completed high school (Yr 12)	3	10
	Completed intermediate school (Yr 10)	7	24
	Unknown	1	3
Employment status	Employed full time	11	38
	Employed part time	5	17
	Retired	13	45
Breslow thickness (mm)	≤1.0	10	34
	1.01-2.0	13	45
	2.01-4.0	5	17
	>4.0	1	3
AJCC* stage of disease	Stage I	19	66
	Stage II	11	38
Histological type	Superficial spreading melanoma	13	45
	Nodular melanoma	4	14
	Lentigo maligna melanoma	2	7
	Not classified	10	34
Anatomical location	Head/neck	6	21
	Trunk	8	27
	Limbs	15	52
Number of primary melanomas	1	23	79
	> 1	6	21
Time since diagnosis of first primary melanoma	0-12 months	1	3
	1-2 years	3	10
	2-5 years	9	31
	> 5 years	16	55
Follow-up clinician	Surgeon	11	38
	Dermatologist	1	3
	Melanoma unit general physician	17	59
Distance from home to melanoma unit in km median (range)		39	(8-609)

*AJCC = American Joint Cancer Committee

Table 3. Summary of patient-perceived benefits and downsides of melanoma follow-up

Benefits	**Downsides**
• *Reassurance of being checked by a skilled specialist* • *Early detection of new melanomas* • *Treatment of other skin cancers, such as BCCs,[*] SCCs[*]* • *Education of melanoma aetiology, diagnosis, treatments, skin self-examination* • *Opportunity to ask questions of specialists* • *Health promotion - sun safe behaviour (for self and family)*	• *Anxiety leading up to and during the follow-up visit* • *Inconvenience of travel to attend visits* • *Lost work time related to follow-up visits* • *Undressing for full body skin examinations*

[*]Basal cell carcinomas, Squamous cell carcinomas

Table 4. Examples of participant quotations that illustrate the main findings of the study

Main finding	**Sample participant quotation**
Perceived benefits of follow-up (Reassurance)	*"He checks everything…he checks between my toes, he checks through my hair thoroughly; he always checks the lymph glands under the arms and in the groin…I always feel when I come out of there that it's my best chance of being told there's nothing there at the moment." (woman, 50-59 years)*
Perceived benefits of follow-up (Early detection)	*"I'm hoping that if anything new is starting they'll pick it up before it gets bad...I guess that's the benefit of going isn't it? You can catch them early." (man, 50-59 years)*
Perceived benefits of follow-up (Education)	*"… the professor explained that it's, that it's like a parabola…in the first 6 months after you've done the operation the chances of reoccurring are reasonably high...and each 6 months that drops down lower until it gets along to the 5% mark..." (man, > 80 years)*
Perceived downsides of follow-up (Anxiety)	*"… there is this lurking feeling in the back in your mind that a melanoma is going to jump up and get you somewhere or it could be a secondary somewhere else that they didn't – that it got away at some stage." (man, 60-69 years)*
Frequency of follow-up	*"When they told me to come now at 12 months intervals I did not get anxious about that, I took that advice and I took it as good news." (man, 60-69 years)*
Views about multiple excisions	*"...those cancer clinics, you know, the doctors are just there to make the dough, they want to cut everything out of everyone because they get more money." (man, 60-69 years)*