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Cover Page Footnote

Ethical approval: Approval for the study was for the study was obtained from the South Eastern Sydney Local Health District Ethics Committee (HREC 15/078). Acknowledgements: Our heartfelt thanks go to the patient participants who provided the rich, textual material on which we have drawn.

“Can I still get a tattoo?” Patients’ experiences across the clinical trajectory for metastatic melanoma: a dynamic narrative model of patient journey

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Abstract

Advanced and metastatic cancer has a complex diagnostic and management profile that places a heavy long-term burden on patients and healthcare systems. Little attention has been given to patients’ experiences across their entire clinical journey. Using a qualitative, longitudinal methodology over a ten-month period, we examined the symptom-to-outcome trajectories of seven people attending a medical oncology clinic at a large, public tertiary referral center in Sydney, Australia. Rather than care being experienced as a largely linear progression through diagnosis, treatment and onto surveillance in which life may return to ‘normal’, participants are embedded in a cyclical clinical pathway. Recurrence or metastases are not a matter of ‘if’ but ‘when’. This model of the patient journey points to a need for longitudinal, person-centered services to support the growing population of people with melanoma.

Keywords

Melanoma, person-centered, patient-centric, patient trajectory, patient journey, narrative, qualitative

Introduction

A model of the clinical journey experienced by particular patient populations from symptom identification to outcome can help healthcare providers to plan appropriate and supportive care.¹ There is a gap in qualitative research that examines and represents patients’ experiences of their clinical journeys. Our research seeks to address that gap.

Most research on patient experience is cross-sectional, taking soundings of the care received at specific points in time and place. The few longitudinal studies of progressive patient experience in the context of cancer typically examine specific aspects of care, such as supportive care,² psychosocial needs,³ or more defined domains such as quality of life status⁴ and informational needs.⁵

Our study aims to add value to this body of literature by understanding how a patient cohort experiences different phases in the overall clinical management of their disease. We investigated the healthcare experiences of people with advanced and metastatic melanoma. Melanoma is a cancer of the pigment cells of the skin. There is evidence that while the incidence of cancer overall is decreasing, cases of melanoma are increasing.⁶ In its rising prevalence, and also in light of the aggressive and recurrent nature of the disease, a multitude of services and healthcare settings are implicated in the pathways to treatment, follow-up and

palliative care. Melanoma is increasingly being conceptualized as a chronic public healthcare problem.⁷⁻¹⁰

Earlier work investigating over 200 web-based personal accounts written by people with melanoma established a meta-view of the healthcare journeys of people with varying stages of melanoma.¹¹ The meta-view identified key phases of the personal patient journey in the progression of health care-events related to disease management. These phases were characterized by ill-defined symptom identification, problematic diagnosis, disfiguring treatment, psychological issues related to lifestyle and sun exposure, longitudinal surveillance requirements and, for some patients, recurrence or metastases. We know from that study that the values and principles of patient-centered care, which are to support people in understanding and managing their own health, may not be consistently applied throughout key phases of the melanoma healthcare journey.

Advanced and metastatic stages of melanoma, involving spread to distant lymph nodes or organs such as the lungs, liver, brain or bone, create a different kind of journey. Visible skin changes that clue people into the possible presence of early stage cutaneous melanoma are not necessarily present in metastatic melanoma. The spread to organs may not be detected until serious physical manifestations are present. Symptom detection, diagnostic pathways, treatment and follow-up care take place in a life-

threatening context.¹² In order to understand these patients better and provide targeted support and care, we need to comprehend and model their journeys. In this paper we investigate a potentially generalisable model of the patient journey for people with advanced or metastatic melanoma.

Method

Participants

Our participants were drawn from a population of people attending medical oncology clinics at a public tertiary referral center in Sydney, Australia. Potential participants were being seen by an oncologist for the disease management of tumours suspected or confirmed to be melanomas.

The inclusion criteria were patients who had a potential or confirmed diagnosis of advanced or metastatic malignant melanoma, over 18 years of age and English-speaking. The period of recruitment was six months, from November 2015 to May 2016. Prospective participants were patients attending for the first time, or ongoing patients of the clinic. Although patients were cared for by multiple doctors, nurses, allied health staff and other specialists, all potential participants were patients of one medical oncologist.

Recruitment

Target participants were screened by the medical oncologist ahead of the scheduled clinic visit. Where

eligible, the oncologist would briefly describe the study and ask the patients if they were interested in meeting with the field researcher. If the patient agreed, the researcher met the patient separately, describing the study and seeking informed consent. Nine (9) participants agreed to join the study and to the publication of de-identified study findings. Two participants died before they could take part in the initial interviews. The others participated in an initial interview of at least 20 minutes in length. Enrolees agreed to be shadowed by the field researcher during clinical consultations and treatments, and to ongoing interviews either in person in a setting of their choice or by phone.

The study ensued over the ten-month period from November 2015 to September 2016, dictated by the personal and health needs of the participants and the logistics of doing in-depth social research of this kind. One participant was found after some weeks into the study to have been misdiagnosed; what was thought initially to be a malignant melanoma on the back of his eye was found not to be. Data collected on that participant to the point of diagnosis have been included because his perspective throughout was that he had a melanoma recurrence, and his experiences were thus from the point of view of someone with melanoma.

Participants' characteristics

Table 1 presents the key demographic characteristics of the seven study participants and the status of their health at diagnosis.

Table 1. Participants' demographic profiles and health histories

Participant	Gender	Age*	Stage ¹	Melanoma/ tumour	Length of time since previous melanoma	How latest diagnosis occurred
PA	F	75+	4	lungs, stomach, skull & brain	20 years	After weeks of becoming forgetful and confused, PA suffered stroke-like symptoms and was taken to hospital where investigations led to the identification of tumours
PB	M	75+	4	left leg lymph nodes, lung	12 years	Ultrasound for deep vein thrombosis (DVTs) identified enlarged lymph glands
PC	M	25+	3-4	right arm lymph nodes	2 months	Enlarged lymph nodes were identified in first surveillance scan after melanoma on back had been excised
PD	F	65+	4	stomach, lung, liver	4.5 years	Fell at home, taken to hospital, investigations led to the identification of tumours
PE	M	85+	1/4	eye	N/A	Scheduled cataract examination identified lump
PF	M	70+	4	rib, spine, kidney	2 years	Investigation of ongoing pain from broken rib led to the identification of tumours
PG	M	70+	4	lung, pancreas	4 years	Investigation of abdominal pain led to the identification of tumours

Data collection

We employed the methodology of interpretive description to collect and analyse our data.¹³ Interpretive description takes a social constructivist and naturalistic approach. The methodology emerged from social science and has been applied most often in nursing research and is intended to generate knowledge that can be translated into practice and policy.¹⁴ Interpretive description is a “second-generation” qualitative approach:¹⁵ it promotes a multidisciplinary research agenda in investigating “complex experiential clinical/practical phenomena”,¹⁶ drawing on methodological principles of grounded theory, ethnography and phenomenology.

Data comprised transcripts of interviews with participants, observational field notes and medical information contributed by the supervising oncologist. This triangulated data collection helped form meta-views of what happened as participants pursued their longitudinal goal of resolving the threats to their lives. Further details on methods are provided elsewhere.¹⁷

Interviews were semi-structured, supported by an interview guide, encouraging an open dialogue and allowing participants to move between ‘question and answer’ mode and ‘story-telling’ mode with the aid of prompt questions. A key prompt word ‘journey’ was used to communicate that the study was interested in the past, present and imagined future of participants’ healthcare experiences.

Analysis

Data were downloaded into the software package NVivo10 (QSR International). The analytic procedures in interpretive description methodology “capitalize on such processes as synthesizing, theorizing and recontextualizing rather than simply sorting and coding”.¹⁸ We coded textual data into themes and iteratively coded the elements and

properties of participants’ descriptions and reflections, classifying them into interpretable categories, mapped progressively into a study framework.

Results

The analysis created a meta-view (see Figure 1); an aggregated narrative of the healthcare journeys of participants structured into four pivotal shifts in patient experience: Initiation; Identification; Action; and Adaption. A significant feature of this meta-view is its circular dynamic pointing to profound and unending dependence on the healthcare system. This contrasts with the ideal experience of healthcare services as a fundamentally linear journey from diagnosis to cure or stability of disease. In this section we report the shifting phases of experiences that define this circular meta-view.

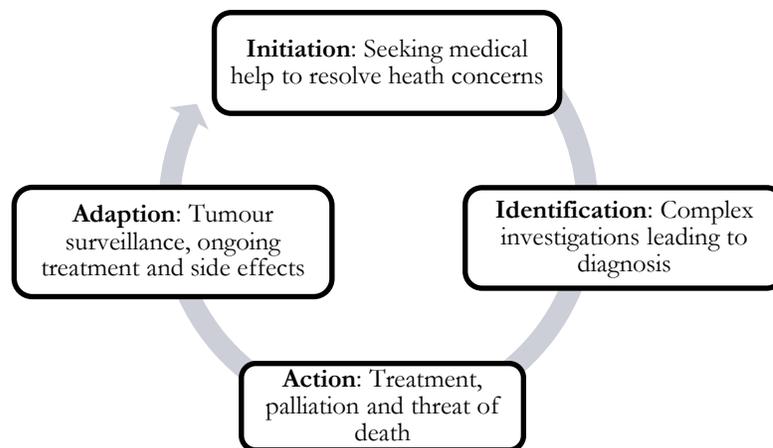
1. Initiation: Seeking medical help

Six of the seven participants had been treated for a primary melanoma in the past. They had completed their long-term surveillance programs and believed they were clear of disease. The reasons they were seeking medical care this time did not relate to melanoma. They were seeking care for: suspected hernia in the groin (PB); confusion and forgetfulness (PA); concern about deep vein thrombosis (DVT) (PB); a fall down a flight of stairs (PD); detection of a lump on the eye during a cataract examination (PE); increasing pain from a fractured rib (PF) and; stomach pain (PG). The final participant (PC) was still in the care pathway for a primary melanoma when enlarged lymph nodes were diagnosed.

Decisions about seeking care

Personal values and beliefs about health management feature strongly. Some participants, such as PB and PG, were quick to seek medical care for health concerns. Given

Figure 1. A meta-view of the clinical trajectory experienced by people with advanced and metastatic melanoma



a history of DVT and a discomfort in his left groin prior to an upcoming flight, PB organized a pre-emptive ultrasound. PG had decided that a recent episode of sudden and severe stomach pain, though resolved and not ongoing, was worthy of further investigation.

Other participants delayed seeking healthcare. PA believed that her ongoing bouts of confusion and forgetfulness indicated stress brought on by current circumstances in her life. She rationalized that the stress was a temporary condition and there was no reason to seek medical advice. PB had been told by a clinician to expect ongoing pain from a fractured rib; though the pain was intensifying, he valued himself as a stoic person and rationalized that since he had an upcoming appointment with a specialist for another health condition, he could wait until then to seek advice. PC described scratching an area on his back for six months before seeing his doctor because he was distracted, dealing with complex personal issues.

2. Identification: Complex investigations leading to diagnosis

This phase was characterized by multiple investigations of possible diagnoses, eventually concluding that a previous melanoma had recurred, advanced or metastasized. Further investigations were often required, including proto-oncogene B-Raf (BRAF) gene mutation testing.

Physical and psychosocial impact of investigations and consultations

Participants noted complex and sometimes confusing pathways to diagnosis, involving logistical challenges, substantial time commitments and, for some, pain. PE observed that scans and consultations were scheduled “one thing at a time” in contrast to being co-ordinated into sequential events in the one location or on the one day. He found it tiring to keep up his commitments in other areas of his life. PF described his pain as shifting from a “three” to a “ten” when moving from lying to sitting to standing during physical examinations. He found that getting in and out of the car to come to the hospital was very difficult and distressing for him and his wife. For PG, an open lung biopsy caused fresh problems: “Until last week when they took a section of lung for a BRAF test no-one would have known I had a serious illness. I felt good and looked fine. Now I'm in pain from the wound and the nerve damage.”

Information pathways and knowledge absorption

Though participants showed interest when clinicians and technicians explained scanning equipment and the meaning of visually represented results, most found it challenging to understand and absorb the information. Six of the seven participants interchangeably referred to CTs (Computed Tomography), MRIs (Magnetic Resonance Imaging) and PET (Positron Emission Tomography) scans, or referred to them generically as ‘scans’. PB expressed personal concern, and concern for others, about the difficulties of staying focused during consultations:

“Because you're the person with the problem, you won't actually hear what the doctor is actually saying. Your partner has got to be primed up ... ask them to listen for you because you won't be able to listen.”

Most participants did not do background reading beyond the information provided by hospital and individual clinicians: “I'm an absolute outsider as far as medical things are concerned even though I've been through all this before. I'm not like some friends who search, trawl the Internet to get information. I don't do that.” (PG). Some were concerned with the negative implications of ‘knowing too much’: “To tell you the truth, they said to read up about it on the internet but it's scary stuff when you start reading and ... being negative just feeds it, got to be positive in it.” (PC)

Impacts of diagnosis

Four of the seven participants (PB, PD, PE, and PG) appreciated the final diagnoses of metastasized melanoma as a result of coincidence and luck. PD, for example, noted: “If I hadn't have fallen down the stairs and been taken to hospital and had the scan, I wouldn't have known I had it... I've just been really lucky.”

Participants also expressed a range of emotions, from devastation through to resignation, that “the beast was back”. PD described her “shock” that she had been given the “all clear” and yet had been diagnosed again: “Every time I have one removed, you think there's going to be no more, this is my last and low and behold, I've got more. So, it's just pretty invasive.” PB commented that he had been expecting a recurrence: “I was essentially cleared. But I always had the view in my subconscious that ... it could come back.”

Relational aspects of care during investigation and diagnosis

Participants' relationships and communication with clinicians and with healthcare providers was a prominent aspect of the Identification phase of the journey. PA deified her oncologist: “As far as I'm concerned, you're god. Whatever you say to do, I'll do.” PE expressed a sense of great fortune in having both an oncologist and ophthalmologist as allies: “I'm just so lucky. Heavens above, to have these two specialists ... Honestly, I nearly cry sometimes. They're so good and do everything for you.” PF wanted to know his life expectancy but excused his oncologist from having to make an accurate prediction: “I know it's impossible to answer, but how long have I got? ... Just a rough ball park, that's all I want to know.” PD empathized with the oncology nurses who had to navigate her collapsed veins: “I feel sorry for them taking blood ... they don't like having to do it. Causing me pain. I try to make it easy on them. Don't worry, that sort of thing.” PG was more critical and struggled with the impact of communication gaps between practitioners: “They're not in touch with each other and you sort of feel ... a link in the chain is broken, and so again it's that feeling of powerlessness.”

3. Action: Treatment, palliation, threat of death

The third segment featured sets of events that filtered out ambiguities and narrowed down treatment options. During this segment, two participants died (PA and PF), which highlighted the time-critical nature of events in melanoma. Treatment options included systemic treatment—medications injected or ingested to shrink or control the tumours—and locoregional treatment such as radiotherapy directed towards a specific problem area such as the brain or bones. Other options focused on palliative care, aiming to minimize the symptoms from the tumours. Our findings identified four key sets of experiences within this segment.

Treatment decisions

Most participants assumed they would take some kind of therapeutic action. “Both mum and dad were clear about the fact that we should do all we can.” (family of PA). PF chose not to be involved in decision-making, saying to the oncologist: “You make all the decisions for me and I go along with whatever you say.” PG described his approach as being one of choosing quality care and then following the directions of those with expertise. The option of seeking second opinions on treatment decisions was raised by two participants. PB noted: “People ... probably don't necessarily realise that they have a choice.” PG described his oncologist as being very open to a second opinion: “He told me what he would be planning to do but also urged me to make contact with Q [oncologist at another treatment facility] and he wrote a referral.”

Response to BRAF testing

The wait time of up to four weeks for BRAF test results, which decide whether a particular type of systemic treatment would work, was a cause of concern for participants because it delayed treatment decisions. Participants described being “annoyed” by the wait and described the waiting period as “suspended animation” and “limbo”.

Though participants commented that BRAF testing had been explained well to them, few made reference to the term ‘BRAF’ in their descriptions of their circumstances, instead referring to ‘the test’ or adopting an analogy used by the oncologist: “We're struggling to find out what the on and off switch is” (family of PA). Participants equated positive BRAF results with a treatment consisting of a course of tablets, whereas they equated immuno-therapy with a treatment involving a course of injections or “chemo” therapy. PD commented: “It was either tablets or injections and he [oncologist] did a test and he's decided the injections were a better way to go for this.”

Physical and psychosocial experiences of treatment

All participants expected to experience difficulties in receiving treatment. Most described being well prepared for immune-therapy treatment and its potential side effects through information pamphlets and tours of treatment

facilities. Hair loss after radiation to the tumour on her skull was described by PA as being of minimal concern. PD was satisfied that the “lumps” and “red marks” on her arms and legs were “routine for the treatment.” Two participants described uncertainty about the side effects they were experiencing. PG was not sure whether his itchiness was a side effect of treatment or a heat rash, but decided against informing his oncologist because the symptoms were controllable and quickly dissipated, and because he did not want treatment to stop. PB, on a clinical trial for Dabrafenib (a drug improving progression-free survival of patients with advanced melanoma with mutations in the BRAF gene), was uncertain about the permanence of almost immediate side effects that included curly hair, body aches, fatigue and additional layers of skin on his feet that had to be “shaved off” every six weeks. He rationalized concern about these effects against the fact that his tumours were shrinking significantly.

PB described the time commitment of his clinical trial as “significant”, comprising attendance at the hospital research unit every three to four weeks for a period of over five years, with a subsequent trial requiring him to travel to the hospital occasionally and be in contact by phone. He noted that he would have “lost sight of the objective” if not for the support of friends and family.

Relational aspects of care during treatment

In the Action phase all participants conveyed a heavy reliance on their oncologist. PA expressed to her oncologist the personal importance of his treatment plan: “You've no idea how much hope you've given me, and all my family, because they've all just dropped their bundles ...” PD identified her oncologist's reputation as a basis for trust in her treatment: “He's got a good success rate apparently so there's every chance that it's going to go [right].” PF gave his oncologist discretionary power over his treatment and relieved him of the burden of treatment failure: “I have every confidence in yourself ... If it works out good, if it works out bad, it doesn't matter, because I know you're doing your best.”

On the other hand, PG expressed concern that information about his health status had not been well curated and communicated: “After the last scans [following a first round of Keytruda, an immunotherapy drug], I found out I have tumours I was never told about ... I was told I had them all the way along. Maybe they didn't see those tumours as relevant ... I assumed they had told me everything.”

4. Adaption: Tumour surveillance and treatment side effects

Of the four participants who progressed into definitive treatment, two transitioned out of the treatment phase and were adapting to their ‘new normal’ by the close of the study. Their descriptions and reflections on key care experiences at this point comprise the following issues.

Health management related to surgery and medication

As a result of extensive surgery to remove all lymph nodes in the left leg as far as the vena cavae, PB developed significant lymphedema. Each night and on vacation he pumped fluid from his leg, and every six to eight weeks he visited a lymphoedema physiotherapist to ensure his leg was being well managed. Side effects from the drug Dabrafenib received while on clinical trial continued to affect PB, though the addition of a second drug, Trametinib (a drug with a different mechanism that helps prolong the benefits of Dabrafenib) had largely rectified the side effects of the first drug. He rationalized the impact of side effects as a “*small price to pay*” for the survival longevity the trial drugs had provided him: “*My feet are still a bit sore, some joints become inflamed—my eyesight is not as good as it was, by a long shot. But I am still alive after seven years on Dabrafenib and now in combo with Trametinib drugs!*”

Tumour surveillance and dependence on healthcare services for life decisions

PB had scans every six months “*and then I have a phone call from X [oncologist] and I find out whether I am going to live or die. I refuse to be down about it. You can't look inward and feel sorry for yourself, it will serve no purpose.*”

At a follow-up consultation a year after surgery to remove most of the lymph nodes in his right arm, PC sought a second opinion regarding the completion of a tattoo on that arm: “*I just got one half done and I wanted to get it finished ... He said I can't get it done because I've had my glands removed. Is that correct?*”

Discussion

The aim of this research was the exploration, description and thematic interpretation of seven unique sets of encounters with health care provision in the context of advanced and metastatic melanoma. While entry into the system and the journey along pathways of care from patients' perspectives are markedly non-routine, our thematic analysis of the data identified four key transitional segments in the commonality of experiences. In this four-segment trajectory model, the second and third segments represent the critical periods of participants' healthcare trajectories, based on rich data which contrast with the ‘bookends’ of the first and fourth segments. The four-phase model encompasses phases of Initiation, Identification, Action and Adaption and reflects the experience of advancement, recurrence or metastases of the disease and the high likelihood of further recurrence. This is differentiated from a model which suggest that populations of people go through a largely linear progression of disease management resulting in cure or disease stasis.

The first segment, Initiation, draws attention to the non skin-related issues that drive people with advanced and

metastatic melanoma to seek healthcare. It points to a need for information and education about metastases from melanoma.

The second segment, Identification, highlights the complexity of diagnostic pathways related to metastatic melanoma. It features needs for individualized compassion and responsiveness in the delivery of medical care, underlined by participants' concern with the physical and logistical demands of appointments and consultations. This stage is also characterized by participants' perceptions of doctors as allies, mentors and oracles in the decision-making process.

The personal impact of timeliness features in the third, Action, segment. The wait times for BRAF test results contrasted with participants' perceived urgency in forming decisive pathways for the management of the disease, creating a ‘hurry up and wait’ dynamic in their trajectory of care. Diagnosis occurring after surveillance programs had been completed—sometimes just weeks after participants had been given the ‘all clear’—points to a possible need for extended periods of intensive surveillance.

The final segment, Adaption, reflects the distinctly circular nature of the care pathway for this patient population. For the two surviving participants, life is forever characterised by the reliance on healthcare services to treat remaining tumours, diagnose new tumours and manage the side effects of past and present therapies. Some patient-focused domains emerged as relevant: the need for personalized care for ongoing pain, lack of mobility and lymphedema as a result of the consequences of surgery and chemical treatment; and compassion from healthcare professionals in relation to the ongoing threat to life imposed by a lack of cure for metastatic melanoma.

Limitations

We believe this to be the first study to locate patients' experiences of recurrent, advanced and metastatic melanoma as a meta-view of the clinical trajectory. One limitation is the small size of the participant group, although paradoxically this allows for the fashioning of a richer descriptive account. A small cohort makes detailed experiential data available for inspection and facilitates understanding of care from multiple vantage points. Correspondingly, it limits the extent to which the data is representative of others.

Data of this type is not standardised, but adaptive to each participant's state of health, living situation and availability. Given the health situations of the individual participants, we did not study other aspects of the participants' lives, including any comorbidities.

Conclusion

This study contributes a model of this patient population's shifting responses to clinical journeys with advanced or metastatic melanoma. The model features a cyclical dynamic that is distinguishable from the ideal linear progression through diagnosis, treatment and onto long-term surveillance. People with advanced and metastatic melanoma must adapt to the side-effects and collateral damage of initial and ongoing treatment and live with the perspective that renewed healthcare concerns are not a matter of 'if' but 'when'.

Our participants perceived the clinicians they interacted with, and particularly their oncologist, not only as medical experts but also as co-curators of their lives. Clinicians' choices influenced the quality of their survivorship, down to such details as whether or not they can complete an unfinished tattoo.

Our findings offer to various stakeholder groups in health care an understanding of the need for longitudinal person-centered services to support this growing patient population. The typology may have merit beyond our patients and may encapsulate other clinical trajectories in a range of chronically life-threatening diseases.

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