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## PUBLIC HEALTH & PRIMARY CARE | RESEARCH ARTICLE

# The plot thickens: Archetypal narrative structure in the melanoma patient journey

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**Abstract:** In this article we present a narrative approach to conceptualizing and representing patients' experiences of healthcare across a trajectory of care. We empirically investigate, analyze and represent the diagnostic and care trajectories of people with the aggressive skin cancer melanoma, conceiving a model of lived narratives in which the patients are the central characters moving through a longitudinal series of events. Melanoma is a malignant form of skin cancer that makes heavy, long-term demands on patients and healthcare resources. The perspectives of people with melanoma are under-represented in studies of melanoma patient experience. In our study, we make that missing perspective visible. From data collected on the pre-symptom ordinary world of the patient through phases of medical care and into resolution of the initial disease presentation, we identify the thick plot of patients' care experiences in an archetypal narrative form of patient journey. Our findings identify the potential of this analytic framework as a flexible methodology for the reflection of outset-to-outcome melanoma care experiences in healthcare policy and practice.

### ABOUT THE AUTHOR

The overarching aim of the research reported in this paper was to produce new qualitative research linking the singular to the common patient experience. As individuals and as a research team our work supports innovation through multidisciplinary investigations into patients' experiences of health practices. We brought together expertise from: the Centre for Healthcare Resilience and Implementation Science in the Australian Institute of Health Innovation at Macquarie University, Australia; the Nelune Comprehensive Cancer Centre at Prince of Wales Hospital, Australia; the Prince of Wales Clinical School in the University of New South Wales, Australia; and, the Translational Cancer Research Network, Australia. Three key areas of proficiency informed the study design: personal accounts of medical and healthcare experiences; clinical oncology; and health services systems and culture improvement. We sought to understand how healthcare can respond to patients' unique and shifting experiences during the phases of clinical journey that are common to all.

### PUBLIC INTEREST STATEMENT

In all stories there is a plot—a set of events that moves the story along by shifting the central character from one location, or state of being, to another. In this article, we present the lived plot of patient journey. We tracked the stories of seven people with advanced, life-threatening skin cancer. We noted their experiences from just before the time they identified that something was not right with their health, through the tests that eventually led to a diagnosis of melanoma, and onto the eventual outcome. We found that the plots of these real-life stories have broadly the same phases as fictional stories, moving from the “ordinary world” into the “special world” and then onto a “new normal”. We discuss how this model may be a useful way for doctors and for patients themselves to understand the experience of being a patient with a life-threatening disease.

**Subjects:** Social Sciences; Medical Sociology; Medicine – Sociology; Behavioral Medicine; Complementary and Integrative Medicine; Public Health Policy and Practice; Preventative Medicine; Behavioral Medicine; General Medicine; Complementary & Alternative Medicine

**Keywords:** melanoma; patient journey; narrative medicine; patient-centered care; medical trajectory; trajectory of care

## 1. Introduction

In the normative narrative of patient-centered healthcare, physicians, ancillary healthcare providers, administrative personnel and ill people are collaborative multi-protagonists in the patient journey story. In recent years this normative tale has been written into policy documents to replace the traditional healthcare narrative in which a physician is the central character and the clinical management of disease is the central plot. Yet healthcare services still struggle to “conceptualize, institutionalize and operationalize” (Dubbin, Chang, & Shim, 2013) patient-centeredness. Patients still tell of being treated as secondary characters in a healthcare provider’s sub-plot. The narrative remains more normative than lived.

This article empirically examines a healthcare narrative in which there is a central protagonist—the patient. In this narrative, healthcare providers are defined by their medical, ancillary and administrative functions in a patient’s bio-psychosocial-medical journey plot. We identified an archetypal personal journey narrative and examined its relevance to experiential data collected in our ethnographic study of the healthcare experiences of a group of people with the skin cancer melanoma. Our analysis of the events of their patient journeys and their reflections on their encounters with healthcare providers is reflected in a plot structure of the archetypal journey narrative.

### 1.1. Background to the study

Knowledge of patients’ experiences is a key evaluation strategy in the efforts to provide quality care (Doyle, Lennox, & Bell, 2013; Richards, Coulter, & Wicks, 2015). However, in the growing milieu of patient experience research, there is a patient perspective that has been largely ignored: the trans-context, compositional experience of healthcare services. To be robustly patient-centric, quality care must be delivered across the spectrum of healthcare services people engage with as they progress on their journeys from illness to outcome.

An obstacle in achieving this goal is our poor comprehension of patients’ healthcare experiences from the global perspective of whole healthcare journeys. The assemblage of organizations, institutions, services and individual healthcare providers a patient transits in the pursuit of health may be disconnected from each other, however these silos of care form an experiential “set” for the patient. This set can be conceived, in literary terms, as the lived personal narrative of patient experience. That narrative, which features the patient as the central character, takes into account all parts of the patient’s journey and can be plotted to comprehend the whole storyline of patient experience.

This idea is, to some extent, reflected in the use of patient journey mapping (Martin, Biswas, Joshi, & Sturmberg, 2014; Trebble, Hansi, Hydes, Smith, & Baker, 2010). Patient journey mapping conventionally represents a patient trajectory in a contained medical context, such as a hospital, however it is increasingly conceived as “the end-to-end sequence of all the steps required to provide clinical care for a patient” (Ben-Tovim, Dougherty, O’Connell, & McGrath, 2008). In this conception, the patient’s point of view is central because only patients are privy to the whole care journey. However, patient journey mapping does not engage with the entire experience of the patient, from symptom identification through to the personal outcome.

In this article we present a meta-narrative approach to longitudinal patient journey mapping. We conceive patient experience as a bio-psychosocial-medical-organizational (Liberati et al., 2015)

phenomenon that constitutes, from the patient perspective, a lived personal narrative. We engage with narratological frameworks for accessing and analyzing those lived personal narratives, undertaking narrative inquiry to investigate individual perceptions of care journeys and employing an archetypal narrative format to represent the patient as the central character in that journey.

### **1.2. Narrative representation of melanoma experience**

Melanoma is a cancer with a broad demographic profile and a rapidly rising incidence around the world (Trakatelli et al., 2012; Walter et al., 2014). In the early stages of the disease, the site of a primary tumor is confined. With a diagnosis at this stage the goal of treatment is cure, which is most often achieved by surgical incision of the tumor and sometimes associated lymph glands. However, melanoma may spread through the blood stream microscopically, or metastasize, eventually manifesting as tumors in parts of the body distant to the skin. The finding of this distant tumor implies an advanced stage of melanoma that is seen as incurable.

Our study involved a population of people with advanced melanoma (Table 1). Diagnosis and treatment, particularly in advanced and metastatic stages of the disease, involve invasive procedures and chemical therapies that yield ranges of collateral damage which must be managed, widening the range of services implicated (Tan, Butow, Boyle, Saw, & O'Reilly, 2014, p. 252), and survival depends on ongoing medical surveillance (Cornish, Holterhues, Van De Poll-Franse, Coebergh, & Nijsten, 2009). Advanced melanoma thus makes heavy, longitudinal demands on patients and healthcare resources. However, the healthcare trajectories of people with advanced and metastatic melanoma are poorly investigated (Stamataki et al., 2015, p. 780). Our study addresses this gap in the literature.

To model the trajectories of people with advanced melanoma as lived personal narratives, we employed the universal Western storytelling convention of the linear sequence in which there is a progression of time and place (Grabes, 2013). Just as a biography or autobiography conveys lived experience as a series of situations and events that occur within a defined context and time period, we conceived of a lived narrative of patient experience as comprising a longitudinal set of events, characters and outcomes that take place between subjective beginning and end points. We sought to identify beginning and end points that structured the lived narrative as occurring from symptom identification through to personal outcomes to the care experience.

The investigation of transformation archetypes in the context of illness and patienthood has been undertaken most notably by Frank (1995, 1998, 2011), though this work focuses largely on identity transformation. This study is the first to use archetypal transformation narrative as an analytic framework by which to comprehend a patient's care trajectory across the set of events, situations and processes that occur from outset of symptom to outcome.

Further, we looked to the ways in which archetypal narrative representations can link the singular to the common patient experience in the trajectories of people with melanoma. A relevant archetypal representation is the transformation narrative. Identified in various forms and examined in innumerable ways by folklorists, psychologists, philosophers, anthropologists, sociologists and literary analysts, the transformation narrative features three broad stages of emplotment—separation, liminality and reorientation. Central characters are displaced from the comfort of their ordinary lives by events beyond their control. In their efforts to return to stasis they enter a “special world” in which they undergo trials and obstacles that present physical, psychological and/or emotional challenges. The protagonist may or may not make it back to the ordinary world—it may be a “new normal” and even death he or she arrives into as a reorientation to self and life. This narrative is depicted in the simplest of stories told and also the most epic. “Stories about people transforming, often agonizingly, from one shape to another are not just ancient, they're primal. They occupied the earliest storytellers and continue to occupy us now” (Murray, 1999, p. 53).

Detailed modeling of the transformation narrative archetype was undertaken by narrative practitioner Joseph Campbell (1949) with modernization of the model undertaken subsequently by Christopher Vogler (1985). In this model separation, liminality and reorientation represent core phases that are supported by sub-phases (see Figure 1):

#### 1.2.1. The ordinary world

**Set-up:** The establishment of the circumstances of the central character prior to disruption.

**1st turning point—The Call:** An inciting incident—or series of incidents—propels the main character out of the circumstances of the ordinary world. He or she may resist the change at first.

**2nd turning point—Crossing the threshold:** The protagonist meets a mentor who provides support to move into the special world.

#### 1.2.2. The special world

**3rd turning point—Road of trials and obstacles:** There is now no turning back. The protagonist faces physical and psychosocial challenges and tests the alliances of strangers.

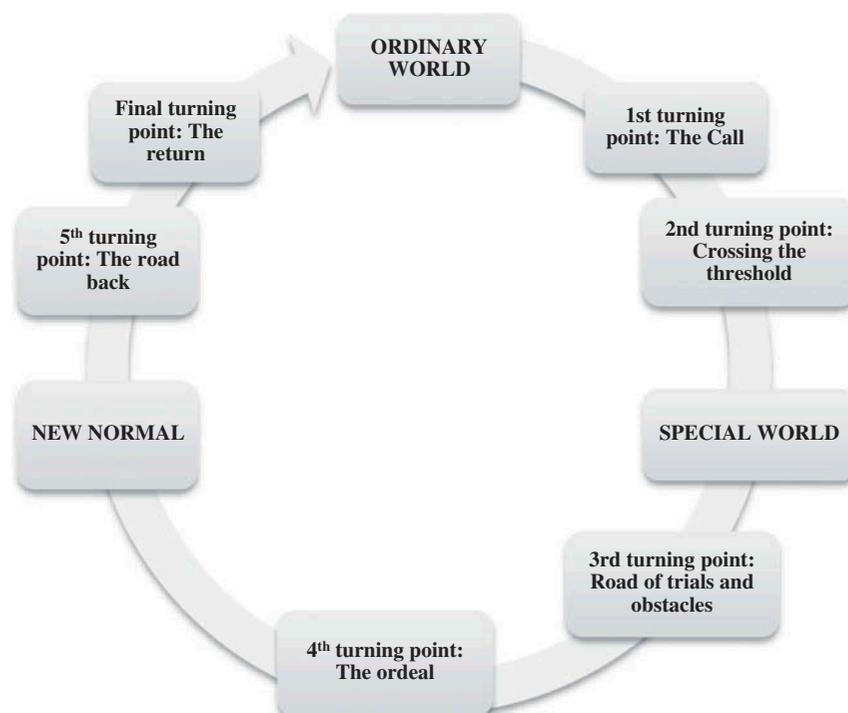
**4<sup>th</sup> turning point—The ordeal:** Now deep in the special world, the protagonist must confront death.

#### 1.2.3. New normal

**5<sup>th</sup> turning point—The road back:** The critical period is over. Though danger still lurks, and there may be fear about the future, the protagonist can move forward.

**Final turning point—The return:** Changed physically and mentally by the events that have occurred, the main character now has to live with who he or she now is and what life will now be.

Figure 1. The archetypal transformation narrative, adapted from the models first produced by Campbell (1949) and modernized by Vogler (1985).



## 2. Method

### 2.1. Recruitment

Participants were recruited from a population of patients of a medical oncology clinic in a public tertiary referral hospital in Sydney, Australia. English-speaking patients over the age of 18 years with suspected or confirmed advanced stage or metastasized melanoma were initially approached by their oncologist with a request to consider involvement in the study. They were told that the study was interested in their experiences of healthcare related to their diagnosis and treatment, and that participation would involve one or more interviews with a researcher and also one or more instances of the researcher observing their consultations with the oncologist, and potentially with other clinicians at the hospital. Patients who expressed an interest were subsequently introduced to the researcher who discussed the study and procedures in detail to obtain informed consent. Participants were recruited over a 6-month period between December 2015 and May 2016.

### 2.2. Participants

In total, nine participants agreed to join the study, however two died before they could take part in the initial interviews. The others consented to participate, allowing the use of any data collected, including any information gathered and observations from the first encounter (HREC 15/078). All but one participant had previous melanomas. The table below indicates the gender and age and health status of the seven enrolled participants.

**Table 1. Demographic characteristics of participants' melanoma at diagnosis**

Participant code	Gender	Age
PA	F	75+
PB	M	75+
PC	M	25+
PD	F	65+
PE	M	85+
PF	M	70+
PG	M	70+

### 2.3. Data collection

#### 2.3.1. Conceptualization

Data were collected up until October 2016. The semi-structured interview is a universal instrument of qualitative research in general (Greenhalgh & Hurwitz, 1999) and narrative inquiry specifically. Its advantage to our study was that core interrogative procedures defined prior to data collection could be shaped “in situ” to meet the needs of participants from varying backgrounds, with varying verbal and interpersonal skills and variable states of health.

Our aim was to facilitate participants in nominating and describing the events and situations that they believed were relevant to include—we wanted our data to be grounded in participants' experience—however we also wanted to ensure that we “captured” all data relevant to each participant's longitudinal patient journey. Thus, our interview structure was designed to produce iterative event identification, so that broad event statements such as “I went to the doctor” might be explored to reveal multiple events that contributed to a participant's experience of visiting a doctor. Based on the list of open-ended phrasing defined by Charmaz (Murray, 1999, p. 53), we used phrases such as “tell me about . . .”, “what happened when . . .” and “could you describe . . .” to initiate interaction, prompt for more comprehensive answers and probe for clarity.

As participants did not enter the study until after their diagnosis of tumors, the data on their patient journeys prior to that time were retrospectively gathered from descriptions by patients and case notes provided by the medical oncologist supervising the study. Thereafter the data set comprised descriptions by patients and their carers of their perceptions of current situations and events, notes taken by the researcher during observation of medical consultations and information from the supervising medical oncologist.

### 2.3.2. Process

Over the period of involvement, the interviews and observations were organized and conducted with individual patients in a variety of settings and timeframes, interspersed with briefings and debriefings about each patient with the oncologist:

**Participant A (PA):** One 90-minute period of observation and interview with the participant and family which occurred prior to, during and after the diagnostic consultation in the oncologist's rooms. Thereafter a metastatic brain tumor advanced quickly and the participant was no longer able to communicate.

**Participant B (PB):** A two-hour interview in the hospital cafeteria with a family member in attendance, followed by periodic discussions/interviews conducted by email.

**Participant C (PC):** One 90-minute period of observation and interview with the participant which occurred prior to, during and after the diagnostic consultation in the oncologist's rooms. Only one interaction was possible.

**Participant D (PD):** One 40-minute period of observation and interview with the participant which occurred prior to and during a consultation with the oncologist. A 120-minute period of observation and interview while the participant underwent chemotherapy. Five monthly discussions/interviews conducted by telephone.

**Participant E (PE):** One 90-minute period of observation and interview with the participant which occurred prior to, during and after the diagnostic consultation in the oncologist's rooms. Five monthly discussions/interviews conducted by telephone.

**Participant F (PF):** One 120-minute period of observation and interview with the participant which occurred prior to, during and after the diagnostic consultation in the oncologist's rooms. Thereafter metastatic tumors advanced quickly and the participant was no longer able to take part in the study.

**Participant G (PG):** A 20-minute introductory meeting at the hospital. A two-hour meeting held in the participant's home. One-hour discussions/interviews conducted periodically by telephone and Skype and ad hoc discussions/interviews conducted by email.

### 2.4. Analysis

The progression of phases in the archetypal transformation narrative (see Figure 1) is driven by “turning points”—a narratological phrase describing events that move a narrative in a new direction (Hühn, 2013, p. 16). The software package NVivo10 (QSR International) was used to store and organize data, and to facilitate analysis. The data were structured into a conventional chronological narrative format, and categorized thematically into the three key narrative segments, and then into seven key plot points. Our approach to thematic analysis was underpinned by the guidelines proposed by Braun and Clarke (2006), which emphasize the formulation and articulation of a per-study rationale for theme identification, in contrast to a prescribed means of analysis.

### 3. Findings

#### 3.1. Participant A (PA)

**Set-up:** PA, who had a melanoma in her leg 20 years previously, is planning her 50<sup>th</sup> wedding anniversary celebrations.

**1st turning point—The Call:** Over a period of six weeks, PA becomes forgetful and confused. She assumes it is temporary stress related to organizing the celebrations and does not seek medical advice.

**2nd turning point—Crossing the threshold:** An ambulance is called when PA is found wandering outside her home in her nightgown during the day, with partial paralysis to one side of her face. She is taken to her local regional hospital.

**3rd turning point—Road of trials and obstacles:** As an inpatient, PA undergoes a series of tests, including MRI and CT scans, which show “hotspots” in her brain, lungs, stomach and skull. She is referred to an oncologist who diagnoses Stage IV secondary melanoma. Her tissue is sent for BRAF gene mutation testing.

**4<sup>th</sup> turning point—The ordeal:** After undergoing radiation therapy for the tumor in her skull, PA suffers seizures and is medicated. She soon dies at home. Her journey ends 20 years after her first melanoma was diagnosed and 12 weeks after the initial symptoms of advanced stage, metastatic melanoma.

#### 3.2. Participant B (PB)

**Set-up:** PB, who had a melanoma in his left leg 12 years earlier, and another in his left arm 12 years prior to that, is dealing with his grown son’s recent death from melanoma.

**1st turning point—The Call:** PB and his wife are planning a vacation overseas to relieve the emotional turmoil of their son’s death. With a history of deep vein thrombosis (DVT), PB organizes a pre-emptive ultrasound. The ultrasound identifies two elongated lymph nodes in his left groin.

**2nd turning point—Crossing the threshold:** PB goes from his regional home to a city hospital for surgery to investigate and remove affected lymph nodes. These are identified as secondary melanomas.

**3rd turning point—Road of trials and obstacles:** Over three weeks PB has three major surgeries in two hospitals to remove most of the lymph nodes from his groin up to his heart. In one operation his bowel is damaged and requires repair. Two of the affected lymph nodes cannot be removed. While recovering from the surgeries, he is told about the first Australian clinical trials for the targeted BRAF gene inhibitor medication, Dabrafenib. His tissue samples, which are preserved in paraffin, are retrieved and sent away to be tested.

**4<sup>th</sup> turning point—The ordeal:** The BRAF results take five weeks and PB is found to have the gene, which means he can be registered for the clinical trial. The trial is suspended just before he is due to begin. He is transferred to another clinical trial for Dabrafenib, being run at a different hospital. Immediate side effects include curly hair, excess skin growth on his feet and aches in his bone joints. He takes part in successive clinical trials over five years.

**5<sup>th</sup> turning point—The road back:** On Dabrafenib, there is 60% shrinkage in his tumors. In conjunction with Trametinib, the tumors are contained. He develops significant lymphedema.

**Final turning point—The return:** He has scans every six months to determine if there are any tumors. Some seven years after the completion of the clinical trial (at the time of the study completion) PB continues to take the Dabrafenib medication. Side effects from the drug are managed with a second drug, Trametinib. He continues to suffer from significant lymphedema

and has a daily routine of pumping out the fluid build-up. PB supports others who have been diagnosed with melanoma.

### **3.3. Participant C (PC)**

**Set-up:** PC is involved in a legal conflict that is occupying much of his time. He is in reasonable health with no history of melanoma.

**1st turning point—The Call:** Over a six-month period, a section of the skin on PC's back becomes increasingly itchy and then begins bleeding.

**2nd turning point—Crossing the threshold:** On the prompting of his family, PC sees a general physician who immediately diagnoses the affected area as melanoma and excises tissue, which is sent for testing.

**3rd turning point—Road of trials and obstacles:** The results of the tissue tests come back as Stage III melanoma. A much wider excision is undertaken of tissue on his back leaving a large scar. Follow-up scans indicate lymph involvement in his right arm.

**4<sup>th</sup> turning point—The ordeal:** PC undergoes extensive surgery to remove most of the lymph nodes in his right arm. His tissue is sent for BRAF testing and he tests positive. This means he is eligible for targeted chemical therapy if required.

**5<sup>th</sup> turning point—The road back:** After postponing a number of follow-up appointments, PC has a scan that identifies more enlarged lymph nodes in his right arm. The node activity, however, is determined to be non-critical.

**Final turning point—The return:** PC is prescribed routine surveillance and returns to his ordinary life.

### **3.4. Participant D (PD)**

**Set-up:** PD is recovering from stomach and lung surgeries for melanoma metastasized from a primary melanoma on her shoulder two years prior to participating in the study.

**1st turning point—The Call:** PD falls down a flight of stairs in her apartment building and is taken by ambulance to the emergency section of her local hospital.

**2nd turning point—Crossing the threshold:** As an in-patient PD undergoes scans that reveal more tumors in her stomach and lungs.

**3rd turning point—Road of trials and obstacles:** Surgery is no longer an option for PD because of the extensive nature of the metastases and the impact of previous surgeries. She is discharged and returns to the hospital as an outpatient for scans and oncology consultations. She is found to be BRAF negative and is prescribed a course of Keytruda to be given at the hospital clinic.

**4<sup>th</sup> turning point—The ordeal:** PD enters a program of three-weekly intravenous Keytruda treatments. Her veins are weak and there are issues getting the cannula in at every treatment. She suffers liver impairment and skin rashes and is temporarily taken off the treatment. On return to the treatment her liver issues become more severe and (at the close of the study) treatment is indefinitely suspended.

### **3.5. Participant E (PE)**

**Set-up:** PE is re-engaging in social activities after a series of illnesses and the removal of a melanoma from his back three months earlier.

**1st turning point—The Call:** During a regular cataract review, a lump is detected on the back of PE's right eye.

**2nd turning point—Crossing the threshold:** After investigations, PE's ophthalmologist determines the lump to be a secondary melanoma. As surgical removal is too risky, PE is referred to an oncologist.

**3rd turning point—Road of trials and obstacles:** The oncologist determines it to be unusual for a solitary secondary melanoma to be present in the eye and refers PE for MRI and PET scans to understand whether other tumors are present. Over the next few weeks the oncologist engages in multi-disciplinary consultations with a radiation oncologist and a specialist ophthalmology team. A month after the lump is first noted it is determined to be benign. PE is no longer an oncology patient (and at this point leaves the study).

### **3.6. Participant F (PF)**

**Set-up:** PF is dealing with a fractured rib that occurred eight weeks previously. As a renal transplant patient with numerous health issues over the years, PF is home-bound much of the time. He had a melanoma removed from his back two years prior to participating in the study.

**1st turning point—The Call:** The pain from the fractured rib is significantly increasing in severity and moving around to PF's lower back. PF has an upcoming consultation with his renal specialist and waits til then to seek advice.

**2nd turning point—Crossing the threshold:** PF is referred for an MRI to understand more about the pain. Cancer is identified in his seventh rib and changes in his second lumbar vertebra suggest the presence of cancer there also, in addition to the identification of a small lump on his kidney. He is referred to the oncology clinic at his local hospital.

**3rd turning point—Road of trials and obstacles:** The oncologist organizes a BRAF test and a PET scan to investigate the changes on PF's second lumbar vertebra and to understand whether other tumors were present. PF is referred to a radiology oncologist for management of the presenting pain, however a decision is made to wait for the results of the PET scan to decide on a treatment regime. A referral is made for an appointment with a home-care palliative care team. As it is the end of the year, there are delays on the PET scan and delays on the palliative care appointment.

**4<sup>th</sup> turning point—The ordeal:** Participant F is brought into the emergency department with bleeding into the epidural space of the spinal canal from a vertebral fracture. Following palliative care, PF dies.

### **3.7. Participant G (PG)**

**Set-up:** PG is enjoying good health and an active social and work life. He had a melanoma on his ear five years previously.

**1st turning point—The Call:** After a sudden onslaught of severe pain in his abdomen, PG consults his general practitioner who suspects appendicitis. A blood test shows heightened levels of white blood cells and PG is referred for a CT scan of his abdomen and pelvis, which coincidentally identify three nodules on his lungs.

**2nd turning point—Crossing the threshold:** A CT scan of his chest confirmed the presence of the nodules in PG's lungs. He is referred to a surgeon who assesses the tumors to be secondary melanoma.

**3rd turning point—Road of trials and obstacles:** The surgeon refers PG for a PET scan, a fine needle lung biopsy for BRAF testing, a brain MRI, and a consultation with an oncologist. Cancer is detected in his lymph nodes and on his pancreas. The tissue from the fine needle biopsy is insufficient so PG undergoes a more conclusive lung biopsy. He suffers a post-operative infection. The BRAF test

results are negative and after a consultation with his oncologist, PG is referred to a specialized melanoma oncology clinic for treatment options.

**4<sup>th</sup> turning point—The ordeal:** PG begins a course of three-weekly intravenous Keytruda treatments. The outcome of the first course of treatments is the growth of some tumors and shrinkage of others. He is put on a second course.

**5<sup>th</sup> turning point—The road back:** After 24 weeks of treatment, he is told that the lung tumours have diminished significantly, and other tumours are diminishing slowly.

**Final turning point—The return:** PG incorporates regular Keytruda infusions and scans into the routine of his life.

#### 4. Discussion

Our findings develop the visibility of the patient as protagonist in the emplotted representation of patient experience as a lived narrative. In the analytic descriptions of these cases, healthcare providers are implicit to the action, and, when identified, are positioned as secondary characters whose qualities and behaviors support or fail to support the patient's journey. Patients and their transitions through the system are the indexical reference point for all that occurs. This patient-centered, multi-disciplinary perceptual framework privileges the story of the patient and can be understood as providing a whole journey perspective that is missing from almost all patient experience research—and particularly from research on the care experiences of people with melanoma. In short, this type of study moves the axial focal point of research from cross-sectional to longitudinal, and from provider-centered to patient-centric.

In choosing to chronicle healthcare experiences of people with advanced stage melanoma we exposed narratives comprising complex diagnostic pathways and multiple healthcare encounters. While the plots of events in each lived narrative comprise care experiences that are specific to the experiences of each participant, commonly as participants progressed from the first into the second “act”, their storylines became more densely populated with healthcare experiences: their plots thickened as their experiences grew more complex. Collecting, analyzing and representing data on complex individual patient journeys is time-consuming and resource-draining yet there is a need for comprehension of longitudinal conceptualizations of patient journeys, especially in the case of aggressive, increasingly prevalent diseases such as melanoma.

We make a case for exploring the usefulness of archetypal transformational phases in narratives as a tool for linking the singular to the common patient experience. The limits of this study, however, relate to the number of participants: with larger resources, a project could investigate the narratives of many people with melanoma in different stages of the disease. Potentially such a project would identify more or different plot points with each of the narrative phases, and also achieve profiling of protagonist and secondary character functions and qualities. Further, our analysis filtered out the minutiae of events that were described by participants or that we observed during data collection, such as specific conversations, descriptions of past healthcare experiences and details of logistic or administrative events. A much more detailed narrative would be achieved by including these details. Nevertheless, longitudinal views of patients' lives from symptom identification to outcome can be achieved through research of this kind, as we show.

Narrative cases, while having low external validity in a quantitative sense, bring experiential knowledge that is new to the qualitative understanding of patient experience in general and melanoma in particular. The plot of events in this study represents the “outer” journey of events that occurred in each participant's story, in the context of a universal narrative structure. The same structure could be adapted also to comprehending the “inner” journey, or psychosocial transformation people undergo as they move through their bio-medical trajectory. The narrative structure could also be used to comprehend the progressive phenomenological experiences of being a patient (Carel & Cooper,

2014), covering such issues as patient-doctor power dynamics and loss of control over one's body. The journey narrative analytic framework provides a flexible methodology for comprehending key experiences and archetypal phases in the lived narratives of people with advanced melanoma.

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