



Received: 18 November 2017
Accepted: 28 May 2018
First Published: 04 June 2018

*Corresponding author: Jeffrey Braithwaite, Australian Institute of Health Innovation, Centre for Healthcare Resilience and Implementation, Macquarie University, Science Level 6 × 75 Talavera Road, NSW 2109, Australia
E-mail: jeffrey.braithwaite@mq.edu.au

Reviewing Editor:
Albert Lee, Centre for Health Education and Health Promotion, The Chinese University of Hong Kong, Hong Kong

Additional information is available at the end of the article

PUBLIC HEALTH & PRIMARY CARE | RESEARCH ARTICLE

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

Klay Lamprell¹, Melvin Chin^{2,3} and Jeffrey Braithwaite^{1*}

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.

Subjects: Social Sciences; Medical Sociology; Medicine - Sociology; Behavioral Medicine; Complementary and Integrative Medicine; Public Health Policy and Practice; Preventative

ABOUT THE AUTHOR

The overarching aim of the research reported in this article 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.

Medicine; Behavioral Medicine; General Medicine; Complementary and 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.

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 + |

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.

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 (2008) 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). 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.

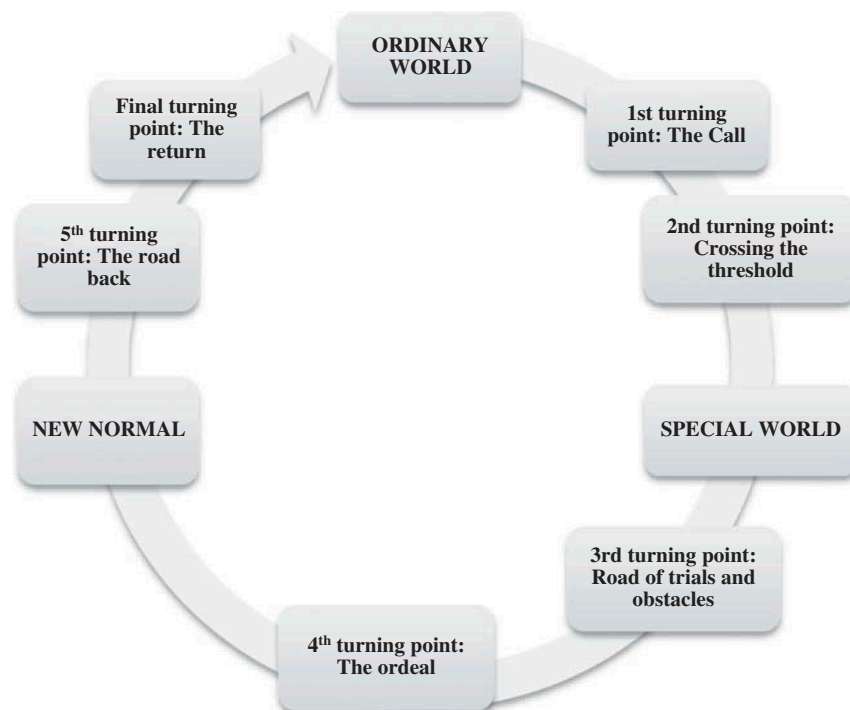
This study is the first to use archetypal transformation narrative as an analytic framework by which to comprehend a patient’s care trajectory across the set of events, situations and processes that occur from outset of symptom to outcome.

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.

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



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.

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.

As participants did not enter the study until after their diagnosis, the data collected on their patient journeys prior to that time was retrospective. Thereafter the data set comprised descriptions by patients and carers of their experiences given in interview, notes taken by the researcher during observation of medical consultations and information from the medical oncologist supervising the study.

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. The ordinary world

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

- PA:** PA, who had a melanoma in her leg 20 years previously, is planning her 50th wedding anniversary celebrations.
- PB:** 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.
- PC:** PC is involved in a legal conflict that is occupying much of his time. He is in reasonable health with no history of melanoma.
- PD:** 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.
- PE:** PE is re-engaging in social activities after a series of illnesses and the removal of a melanoma from his back three months earlier.
- PF:** 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.
- PG:** 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: *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.*

- PA:** 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.
- PB:** PB and his wife are planning a vacation 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.
- PC:** Over a six-month period a section of PC's back becomes increasingly itchy and then begins bleeding.
- PD:** PD falls down a flight of stairs in her apartment building and is taken by ambulance to the emergency section of her local hospital.
- PE:** During a regular cataract review, a lump is detected on the back of PE's right eye.
- PF:** The pain from the 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 until then to seek advice.
- PG:** 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: *The protagonist meets a mentor who provides support to move into the special world.*

- PA:** 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.
- PB:** 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.
- PC:** 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.
- PD:** As an in-patient PD undergoes scans that reveal more tumors in her stomach and lungs.
- PE:** 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.
- PF:** 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.
- PG:** 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.

4. 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.*

- PA:** 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.
- PB:** 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.

- PC:** 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.
- PD:** 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 at the hospital clinic.
- PE:** 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).
- PF:** 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 the decision is 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 palliative care appointment.
- PG:** 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.

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

- PA:** After undergoing radiation therapy for the tumor in her skull, PA suffers seizures from the brain tumor and is medicated. She dies at home 20 years after her melanoma journey first began, and 12 weeks after her journey of advanced stage melanoma began.
- PB:** 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, however he is transferred to another clinical trial for Dabrafenib, being run at a different hospital. For five years he attends a clinic for treatments. Immediate side effects include curly hair, excess skin growth on his feet and aches in his bone joints.
- PC:** 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 so that he is eligible for targeted chemical therapy if required.
- PD:** 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.
- PF:** Participant F is brought into emergency with bleeding into the epidural space of the spinal canal from a vertebral fracture. Following palliative care, participant F dies.
- PG:** Participant G 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, which was continuing at the time the study was completed.

5. “New normal”

5th 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.*

PB: On Dabrafenib, there is 60 per cent shrinkage in his tumors. In conjunction with Trametinib, the tumors are contained. He develops significant lymphedema.

PC: After postponing follow-up appointments, PC has a scan that identifies more enlarged lymph nodes in his right arm. The activity, however, is determined to be non-critical.

PG: PG continues his second course of treatment.

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.*

PB: 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. He has scans every six months to determine if there are any tumors. B supports others who have been diagnosed with melanoma.

PC: PC is prescribed routine surveillance and returns to his ordinary life.

PG: PG's second course of treatment becomes part of his life.

6. 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.

Acknowledgements

The authors express deep gratitude to the participants and their families for their generous involvement in this research.

Funding

This work was supported by the National Health and Medical Research Council, Program Grant [APP1054146] and Centres of Research Excellence Grant in Implementation Science in Oncology [APP1135048]; KL’s work is supported by the provision of an Australian Postgraduate Scholarship.

Competing interests

The authors declare no competing interests.

Author details

Klay Lamprell¹

E-mail: klaylamprell@gmail.com

Melvin Chin^{2,3}

E-mail: Melvin.Chin@health.nsw.gov.au

ORCID ID: <http://orcid.org/0000-0002-9972-8119>

Jeffrey Braithwaite¹

E-mail: jeffrey.braithwaite@mq.edu.au

ORCID ID: <http://orcid.org/0000-0003-0296-4957>

¹ Australian Institute of Health Innovation, Centre for Healthcare Resilience and Implementation Science, Macquarie University, 75 Talavera Road, NSW, Level 6, 2109, Australia.

² Prince of Wales Clinical School, UNSW Medicine, Sydney, Australia.

³ Department of Medical Oncology, Prince of Wales Hospital, Randwick, Sydney, Australia.

Ethical approval

Approval for the study was obtained from the South Eastern Sydney Local Health District Ethics Committee (HREC 15/078).

Contributors

KL designed the study, prepared the study materials, performed the participant interviews, analyzed the data, initiated the paper, reviewed the literature and wrote the first draft. MC contributed to the facilitation of the study, interpretation and writing of the manuscript. JB contributed to meetings as the research unfolded and multiple drafts with the addition of appropriate ideas and editing. All authors contributed to and approved the final manuscript.

Disclosure statement

No potential conflict of interest was reported by the authors.

Citation information

Cite this article as: The plot thickens: Archetypal narrative structure in the melanoma patient journey, Klay Lamprell, Melvin Chin & Jeffrey Braithwaite, *Cogent Medicine* (2018), 5: 1484053.

References

- Ben-Tovim, D. I., Dougherty, M. L., O’Connell, T. J., & McGrath, K. M. (2008). Patient journeys: The process of clinical redesign. *Medical Journal of Australia*, 188(6), 14.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. doi:10.1191/1478088706qp0630a
- Campbell, J. (1949). *The hero with a thousand faces*. New York, NY: Pantheon Books.
- Campbell, J. (2008). *The hero with a thousand faces* (3rd ed.). Novato CA: New World Library.
- Carel, H., & Cooper, R. (2014). *Health, illness and disease: Philosophical essays*. Abingdon, UK: Taylor & Francis.
- Cornish, D., Holterhues, C., van de Poll-Franse, L. V., Coebergh, J. W., & Nijsten, T. (2009). A systematic review of health-related quality of life in cutaneous melanoma. *Annals of Oncology*, 20(Suppl 6), vi51–58. doi:10.1093/annonc/mdp255
- Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*, 3(1), e001570. doi:10.1136/bmjopen-2012-001570
- Dubbin, L. A., Chang, J. S., & Shim, J. K. (2013). Cultural health capital and the interactional dynamics of patient-centered care. *Social Science & Medicine*, 93, 113–120. doi:10.1016/j.socscimed.2013.06.014
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: University of Chicago Press.
- Frank, A. W. (1998). Just listening: Narrative and deep illness. *Families, Systems, & Health*, 16(3), 197–212. doi:10.1037/h0089849
- Frank, A. W. (2011). Practicing dialogical narrative analysis. In J. A. Holstein & J. F. Gubrium (Eds.), *Varieties of narrative analysis*. Thousand Oaks, CA: SAGE Publications.
- Grabes, H. (2013). Sequentiality. In P. Hühn, J. Pier, W. Schmid, & J. Schönert (Eds.), *The living handbook of narratology*. Hamburg University, Hamburg Germany.
- Greenhalgh, T., & Hurwitz, B. (1999). Why study narrative? What is narrative? *British Medical Journal*, 318(7175), 48–50. doi:10.1136/bmj.318.7175.48
- Hühn, P. (2013). Event and eventfulness. In P. Hühn, J. Pier, W. Schmid, & J. Schönert (Eds.), *The living handbook of narratology*. Hamburg: Hamburg University.
- Liberati, E. G., Gorli, M., Moja, L., Galuppo, L., Ripamonti, S., & Scaratti, G. (2015). Exploring the practice of patient centered care: The role of ethnography and reflexivity. *Social Science & Medicine*, 133, 45–52. doi:10.1016/j.socscimed.2015.03.050
- Martin, C. M., Biswas, R., Joshi, A., & Sturmberg, J. (2014). Patient Journey Systems (PaJS): Narratives and evidence for a paradigm shift. Part 1. In R. Biswas & C. Martin (Eds.), *User-driven healthcare and narrative medicine: Utilizing collaborative social networks and technologies* (Vol. 1). Hershey, PA: IGI Global.

- Murray, M. (1999). The storied nature of health and illness. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 47–63). London: Sage.
- Richards, T., Coulter, A., & Wicks, P. (2015). Time to deliver patient centred care. *BMJ*, 350, h530. doi:10.1136/bmj.h530
- Stamatakis, Z., Brunton, L., Lorigan, P., Green, A. C., Newton-Bishop, J., & Molassiotis, A. (2015). Assessing the impact of diagnosis and the related supportive care needs in patients with cutaneous melanoma. *Support Care Cancer*, 23(3), 779–789. doi:10.1007/s00520-014-2414-x
- Tan, J. D., Butow, P. N., Boyle, F. M., Saw, R. P. M., & O'Reilly, A. J. (2014). A qualitative assessment of psychosocial impact, coping and adjustment in high-risk melanoma patients and caregivers. *Melanoma Research*, 24(3), 252–260. doi:10.1097/cmr.0000000000000059
- Trakatelli, M., Siskou, S., Proby, C., Tiplica, G. S., Hinrichs, B., Altsitsiadis, E., ... Stockfleth, E. (2012). The patient journey: A report of skin cancer care across Europe. *British Journal of Dermatology*, 167, 43–52. doi:10.1111/j.1365-2133.2012.11086.x
- Trebble, T. M., Hansi, N., Hydes, T., Smith, M. A., & Baker, M. (2010). Process mapping the patient journey: An introduction. *BMJ*, 341, c4078. doi:10.1136/bmj.c4078
- Vogler, C. (1985). *A practical guide to Joseph Campbell's The Hero with a thousand faces*. Retrieved from http://www.thewritersjourney.com/hero's_journey.htm
- Vogler, C. (1998). *The Writer's Journey: Mythic structure for writers*. Studio City, CA: Michael Wiese Productions.
- Walter, F. M., Birt, L., Cavers, D., Scott, S. D., Emery, J., Burrows, N., ... Campbell, C. (2014). 'This isn't what mine looked like': A qualitative study of symptom appraisal and help seeking in people recently diagnosed with melanoma. *BMJ Open*, 4(7), e005566. doi:10.1136/bmjopen-2014-005566



© 2018 The Author(s). This open access article is distributed under a Creative Commons Attribution (CC-BY) 4.0 license.

You are free to:
Share — copy and redistribute the material in any medium or format.
Adapt — remix, transform, and build upon the material for any purpose, even commercially.
The licensor cannot revoke these freedoms as long as you follow the license terms.

Under the following terms:

Attribution — You must give appropriate credit, provide a link to the license, and indicate if changes were made.
You may do so in any reasonable manner, but not in any way that suggests the licensor endorses you or your use.
No additional restrictions

You may not apply legal terms or technological measures that legally restrict others from doing anything the license permits.



Cogent Medicine (ISSN: 2331-205X) is published by Cogent OA, part of Taylor & Francis Group.

Publishing with Cogent OA ensures:

- Immediate, universal access to your article on publication
- High visibility and discoverability via the Cogent OA website as well as Taylor & Francis Online
- Download and citation statistics for your article
- Rapid online publication
- Input from, and dialog with, expert editors and editorial boards
- Retention of full copyright of your article
- Guaranteed legacy preservation of your article
- Discounts and waivers for authors in developing regions

Submit your manuscript to a Cogent OA journal at www.CogentOA.com

