

# **Meta-narratives in the melanoma patient journey**

A medical humanities approach to understanding patients' experiences

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“The care of the sick unfolds in stories.” (Rita Charon 2012)



Het zieke meisje / The sick girl c.1660/62

Jan Steen (1626–1679)

The Mauritshuis collection, The Hague

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## **Abstract**

In the transitioning of healthcare from provider-centred to patient-centred care, the ways patients experience the system, its providers and their own illness has come increasingly into focus. How patients experience healthcare journeys is under-researched. This thesis investigates the nuances and textures of these journeys in the case of patients with the skin cancer melanoma. Melanoma is a disease that is aggressive and recurrent, and its incidence is rising throughout the Western world. The burden on patient populations and the healthcare systems they use is considerable. This thesis asks ‘how do people with melanoma experience healthcare from the outset of the disease through to outcome’? Triangulated research was undertaken involving a six-month ethnographic study of seven people with advanced melanoma attending a medical oncology clinic at a public tertiary referral centre in Sydney, Australia and a three-month meta-narrative analysis of 214 personal accounts of melanoma published to websites in Australia, New Zealand, the United States and the United Kingdom. The research adopted a narrative view of melanoma patient experience as a phenomenon under study. This view was underscored by the use of narrative methods in data collection, the organisation of the data as a narrative research text, the use of narrative theory in the analysis of the data and the framing of the research findings in a narrative representation of the melanoma patient experience. The findings of the triangulated study were synthesised with what is known about melanoma patients’ care experiences from extant, topic-based qualitative studies. This thesis makes an original contribution by identifying, from the patient perspective, issues including: symptom identification and diagnosis of melanoma in the context of comorbid conditions; dissonance between physicians’ minimisation of the likelihood of melanoma and a subsequent diagnosis; under-preparation for the physical and psychosocial disruption of diagnostic biopsies and surgical treatments; the impact of long waiting periods for results of BRAF tests; difficulties obtaining information about clinical trials; and unclear expectations about the success of treatment and the likelihood of recurrence. The empirical, methodological and pragmatic contributions of the research include: meta-views of the healthcare journeys that people with melanoma take; archives of detailed patient perspectives on melanoma healthcare journeys; the establishment of a medical humanities approach to investigating patient experience conjoining the precepts of social science research and the heuristics of literary analysis; and information that can be used in policy and practice to manage the healthcare needs of people with melanoma and accommodate the growing burden of the disease on healthcare systems.

### **Declaration**

I certify that the work in this thesis entitled 'Meta-narratives of the melanoma patient journey: A medical humanities approach to understanding patients' experiences' has not previously been submitted for a degree, nor has it been submitted as part of the requirements for a degree to any other university or institution other than Macquarie University.

I also certify that the thesis is an original piece of work and it has been written by me. Any help and assistance that I have received in my research work and the preparation of the thesis itself have been appropriately acknowledged.

In addition, I certify that all information sources and literature used are indicated in the thesis.

Klay Lamprell (Student ID: 78183340) January 2017

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A PhD is a quest narrative in the making—a story of personal journey, of transition and of transformation. The characters that populate the narrative are crucial to the outcome; with their support and guidance the candidate who plays the central role can navigate herself to the end of the story. So many people saw me through my PhD and I thank each of them for everything they said or did to encourage and advise me.

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## Terminology and concepts

**BRAF:** “A human gene that makes a protein called B-Raf. It is involved in sending signals inside cells which direct their growth. In some cancers, this gene has mutated. Drugs that target these mutations and thereby treat these cancers have been developed, such as vemurafenib and dabrafenib” (MIA 2014).

**Emplotment:** The organisation of a series of events into a time sequence that has meaning. ‘The king died and then the queen died’ is a sentence that describes events in a time sequence. ‘The king died and then the queen died of grief’ orders events into a time sequence that has meaning (Forster 1927/1955:86).

**Keytruda:** The colloquial name for pembrolizumab, which is a prescription medicine used to treat melanoma when the cancer has spread or cannot be removed by surgery.

**Lifeworld:** An expression derived from the German word *Lebenswelt*, most often associated with the German philosopher Edmund Husserl (Husserl and Carr 1936/1970); it expresses the idea of immediately lived experience as distinct from reflection on and representation of experience.

**Lymphoedema:** A common side effect of lymph node dissection surgery in which there is a swelling of limbs caused by blockages in the lymphatic drainage system post-surgery (MIA 2017).

**Meta-ethnographic review:** A form of literature review in which empirical studies are synthesised to derive concepts that “may not have been explicitly identified in any of the original empirical studies” (Campbell, Pound et al. 2003:673).

**Meta-narrative:** A grand narrative; a narrative that comprises the overarching plot of a collective of stories; an underlying storyline behind the surface narrative in which there are elements reinforcing cultural norms (*Macquarie* 2016).

**Meta-narrative analysis:** A form of literature review, developed by Greenhalgh et al. (Greenhalgh, Robert et al. 2005) in which empirical studies are synthesised to comprehend the overarching storylines of research traditions within particular fields of study.

**Narrative:** A story of events, experiences or the like, whether true or fictitious; narrative matter, as in literary work; the act or process of narrating; the rationale for a sequence of events, presented as the underlying explanation; that narrates (*Macquarie* 2016).

**Narrativity:** The variable narrative effects achieved in a text or act of expression.

**Pathography:** A written account of an experience of illness (Hawkins 1999, Van Der Weyden 2002).

**‘Patient experience’ and ‘patient journey’:** In the “experience era” (Wolf 2016) these terms have been adapted as noun phrases<sup>1</sup>.

**Protagonist:** The central character in a story.

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<sup>1</sup> These terms are explored further within the body of the thesis.

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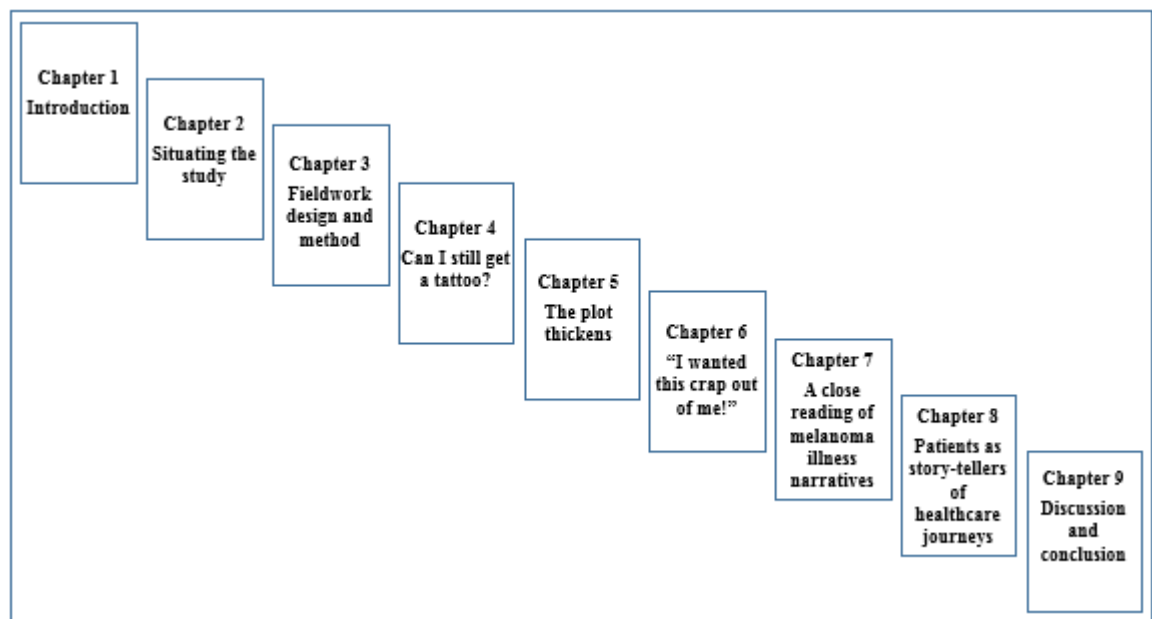
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## Thesis structure

In the structure of the thesis, I move in three parts from an introduction (Chapter 1) through to a discussion and conclusion (Chapter 9). Part One comprises three chapters, 1–3. Part Two contains the five submitted and published chapters (4–8). Part Three contains Chapter 9 and completes the thesis as presented. The diagram shows this schematically. At the start of each chapter, the diagram acts as a guidepost for navigation through the thesis.



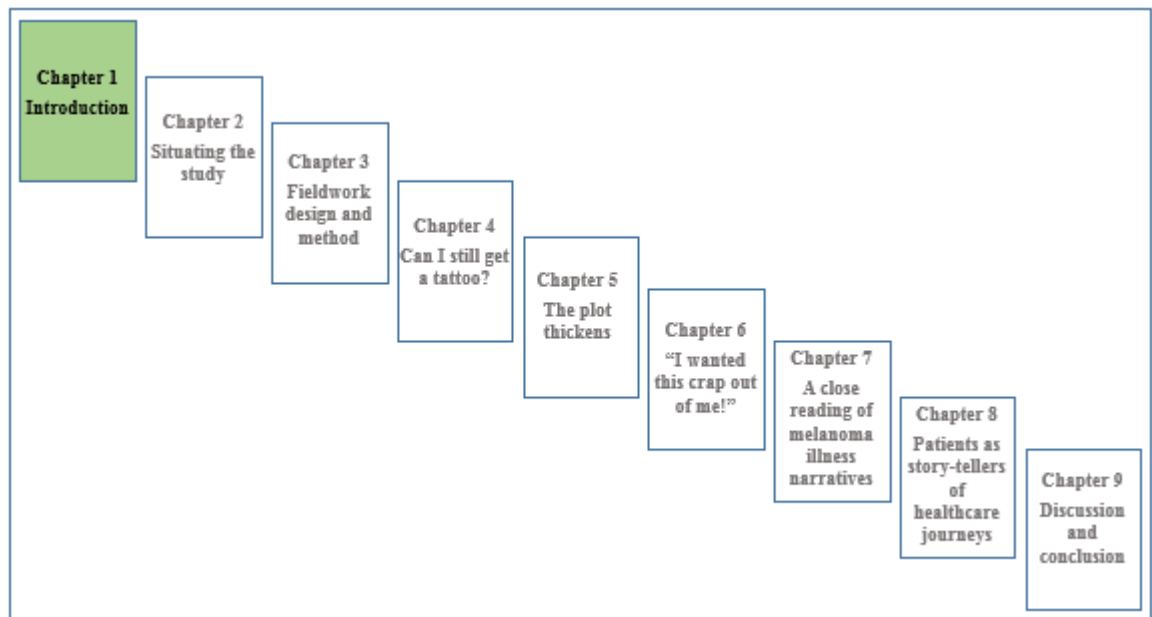
## **Part One**

Chapter 1: Introduction

Chapter 2: Situating the study

Chapter 3: Fieldwork design and method

# 1 Introduction



*“So this is how it goes... once you have melanoma. It’s a LIFE LONG DEAL. It’s never over.”* MPNA\_023P

People experience medical services and ancillary healthcare as a function of their illness. They bring the private life of their illness into the public domain. They leave the comfort of their homes to sit in waiting rooms and lie on hospital beds. They submit their lives for the time that they are patients to reconfiguration by other people’s values, norms and knowledge because they have a great need to be made well and they cannot do it by themselves. The experience of being a patient, even in the most ordinary of its conceptions, is no easy thing. Being a patient with a disease that is life-threatening raises the stakes of patienthood. For people with melanoma, a malignant, aggressive form of skin cancer, the experience of being a patient can unfold over long periods of time through diagnostic, treatment and follow-up phases of care and into lifelong surveillance. It is an experience of transition through multiple medical settings and into and out of multiple relationships with healthcare providers over the course of a disease that may then transition into recurrence. It is a patient journey that is under-investigated in qualitative research on melanoma. This thesis investigates that patient journey, from the patient’s point of view.

## Introduction to the thesis

“Narrative approaches to the study of lives” (Sandelowski 1991:162) make sense because narrative is an inherent mode of telling something about one’s life, and comprehending what someone is telling. Through narrative we are capable of

representing unique experiences in a shared framework that makes those experiences accessible to others. Thus the universal human capacity to narrate experience in some form or other makes it an “international, transhistorical, transcultural” (Barthes 1988:79) means of translating “knowing into telling” (White 1980:5). Narrative research in social science seeks to comprehend social phenomena, such as patients’ experiences, by collecting and investigating narrative artefacts, such as written stories and transcripts of oral stories and narrative talk in interview.

However, as we see in Chapter 2, there is confusion and debate about what is meant by “narrative as method” (Bamberg 2012:2) in social science research. This debate centres on the narrativity<sup>2</sup> of the research artefacts—journal papers, conference materials and books—that are produced as a result of using discourse as a mode of inquiry. The nuances of narrative as method are relevant to the representation in academic literature of patients’ experiences of healthcare and transitions through medical services and healthcare organisations and systems.

A narrative of an experience features the idiosyncratic emplotment of events, thoughts and feelings between a subjectively selected beginning and end of a period of time.<sup>3</sup> This process creates a coherent continuity of personal perspective. Social science researchers engaged in narrative inquiry have no obligation to produce a research artefact that reflects the over-time emplotment of experience that characterises participants’ descriptions of events and responses to events. Rather, events, thoughts and feelings identified through discourse with study participants can be—and often are—analysed thematically and cross-sectionally and represented as “snapshots” (Broom and Tovey 2008:96). The experiences narrated by study participants thus become disconnected in the research findings from the subjective temporality of personal emplotment and the longitudinal perspective that is an intrinsic feature of “*how* things are experienced” (Dewey 1929:4a)<sup>4</sup>. In narrative inquiry into patient experience research, the ‘journey’ of the study participant, which metaphorically describes a subjective transition through elements of an experience as well as physical transitions through biomedical phases and through clinical and healthcare settings, is not

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<sup>2</sup> This word ‘narrativity’, though summarily described in the terminology list at the start of the thesis, drives considerable debate among narrative analysts. For a comprehensive view of the debate, see: Abbott, H. P. (2011). Narrativity. Living Handbook of Narratology. P. Hühn, J. C. Meister, J. Pier and W. Schmid. Hamburg, University of Hamburg.

<sup>3</sup> White explains a set of events in time as a chronicle. A chronicle, he says, becomes a narrative when the content is shaped to have meaning in the perspective of the narrator, a process that occurs primarily through the subjective emplotment of events from a subjective beginning to a subjective end resulting in a continuity of representation of personal experience. White, H. (1980). "The value of narrativity in the representation of reality." *Critical Inquiry* 7(1).

<sup>4</sup> Author’s emphasis.

necessarily—and not often—a feature of the reported findings, unless the patient trajectory is the specific interest of the research.

This thesis proposes that the concept of patient journey, in addition to its use as a form of clinical audit in which patient journey mapping<sup>5</sup> informs clinical process redesign, is a powerful, overarching means of conceiving and representing how patients experience medical and ancillary healthcare. The concept of patient journey accounts for the patient perspective of healthcare experiences as a transitory, longitudinal and horizontal movement across healthcare services, temporally located within the totality of a person's life. The common features of collectively connected patient journeys can be constituted as a meta-narrative, or “overarching storyline” (Greenhalgh, Robert et al. 2005) within which patient experiences occur. Further, the findings that emerge from thematically analysed, cross-sectionally situated studies of patient experience can potentially be represented as plot points within a patient journey meta-narrative. The concept of patient journey meta-narrative thus offers a patient-centred framework for gathering disparate patient experience research findings into an overarching view of singular and/or collective patient experience.

The patient journey meta-narrative may be particularly relevant as an approach to understanding and representing experiences of care related to melanoma, which is an under-explored arena. Melanoma is a heterogeneous skin cancer that comprises over ten per cent of all new cancer cases in Australia (Kasparian, Mireskandari et al. 2016). It is responsible for almost four per cent of deaths from cancer and it is the fourth most common cancer nationally (McLoone, Watts et al. 2013). Worldwide, melanoma is on the rise (Banerjee, Lao et al. 2016) and it is being characterised as a ‘chronic’ public healthcare problem (Cornish, Holterhues et al. 2009, Joshua 2012, Winstanley, White et al. 2013, Sandru, Voinea et al. 2014).

Melanoma presents special challenges within the domain of cancer because it can be a complex disease to diagnose and to manage, and the treatment options are limited for those in advanced stages. While the changes in melanoma treatment driven by the new focus on personalised medicine have been described as a “renaissance” (Bernatchez, Cooper et al. 2016), the disease is still considered incurable (Hill, Robinson et al. 2015). Further, people who have been treated for one melanoma are nine times more likely

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<sup>5</sup> Patient journey mapping examines how patients navigate between particular areas of a healthcare domain “using the patient's perspective to identify problems and suggest improvements” Trebble, T. M., N. Hansi, T. Hydes, M. A. Smith and M. Baker (2010). “Process mapping the patient journey: an introduction.” *BMJ* **341**.



than the general population to develop another primary melanoma (McLoone, Watts et al. 2013), driving an interest in the close monitoring of high-risk patients (Watts, Cust et al. 2016). Given the number of healthcare services and healthcare settings involved from diagnosis to treatment and into follow-up and surveillance, every instance of the disease constitutes a longitudinal burden on a person and on the healthcare systems that person uses. Comprehending the progressive healthcare experiences that feature in a melanoma patient's journey is a means of preparing for, and managing, that burden. Consequently there is emerging interest in melanoma patients' experiences of care as an area of inquiry that is discrete from the wider interest in patients' experiences of cancer. As yet, however, the quantitative perspective dominates the research landscape. As the review of relevant literature in Chapter 2 establishes, there is very little qualitative investigation into melanoma patients' perspectives on particular care experiences and on their care experience overall (Barker, Kumar et al. 2011).

In this study, I undertake a triangulated qualitative investigation into the care experiences of people with melanoma in the context of their overall patient journey and examine multiple narrative perspectives of that patient journey. I explore narrative modes of inquiry and representations of melanoma patient experience as meta-narratives of patient journey. In doing so, I connect the structures of narrative with the structures of patient journey experience (Mattingly 1998:24). The thesis enacts narrative as a system of understanding (Brooks 1992) melanoma patient experience—a rich, textured system of understanding that adds to extant empirical knowledge.

This approach situates the thesis in the cross-disciplinary arena of medical humanities where narratology provides for a nexus between narrative inquiry and narrative theory. Narratology is a multi-disciplinary arena that identifies “the logic, principles, and practices of narrative representation” (Meister 2014:1). Narratology is invested in the study of narrative as both a process and a product of that process. As such it offers the concepts and tools by which to understand the action of narrative inquiry in gathering data on patient experience, and to differentiate between the ways that patients narrate their experiences and the ways that researchers reflect that narrative data in their research texts. It provides the ideas and language with which to comprehend and discuss the properties of narrative that are reflected in patient journeys through healthcare systems. It holds the heuristic key to empirical work that aims to investigate both the content and structural properties of non-fiction stories.

## 1.1 Narrative as a system of understanding experience

As a process, narrative is a ‘wrangling’ mechanism by which we bring “the essence of something into view” (Charon 2006:2). Narrative helps to order our experiences of events and relationships, and our thoughts and feelings about those experiences of events and relationships, into something memorable and ‘tellable’. At the crux of the function of narrative are the management of time and the temporality of experience. In our experiencing of an event, we bring together the past, the present and the imagined future, and then our experience of that event, which was current, is immediately in the past and the next experience occurs and so the process goes on, leaping back, forth and sideways (Brough and Husserl 1991). Narrative is a means of settling that messy abstract business into tangible form. Philosopher Paul Ricoeur claimed: “Time becomes human to the extent that it is articulated through a narrative mode” (Ricoeur, McLaughlin et al. 2012:52). In his view, the key process in narrative as a system of understanding and representing experience is the subjective emplotment of events and experiences in time.

Through emplotment, we order subjective accounts of events and experiences into a framework of a beginning, middle and end with personal causality linking the dimensions. This narrative order, as Meretoja explains it, is not pre-given, “but is rather a creative reorganization or reconstruction of reality, ‘grasping together’ experiences and events in a way that brings together the order and disorder—or *concordance* and *discordance*—that characterize our experiences” (Meretoja 2014:98).<sup>6</sup> It is a personal act because the ‘emplotter’ must choose which aspects of an experience to include in the account, where to start the story and where to end it. However it is also a collective act because it uses agreed principles, as in a grammar. This structuralist view does not discount the other ways that “storytelling engages an audience in the experience of the narrator” (Riessman 2008), such as the use of suspense, curiosity and surprise (Sternberg 1993:65/142). The plot, however, is the “principle of interconnectedness and intention which we cannot do without in moving through the discrete elements—incidents, episodes, actions—of a narrative” (Brooks 1992).

Emplotting a patient’s narrative—or a collective of patients’ narratives—from symptom identification through to outcome is a perspective-framing, meaning-making dynamic in qualitative research. Agency in emplotment is central to the epistemological

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<sup>6</sup> Author’s emphasis.

commitment of a narrative methodology. In qualitative interviews, participants may be asked to plot their own stories of experiences or emplotment may occur as a guided activity, with the participant and researcher co-creating the story that is told. “Stories are not simply texts produced by storytellers but they emerge in certain situations because they are encouraged by certain coaxers, coaches and coercers and they are interpreted by certain consumers, readers and audiences” (Murray 1999:15). In that process of co-creation, researchers choose whether to facilitate or limit participants’ emplotment of their experiences according to their subjective perspectives on when an experience began, when it ended and what happened in between. Then, in the analysis of the data, the plot structure of the stories of experience that formed in discourse with participants can be replicated (by re-telling the patient’s story), or interpreted according to a specific plot structure (by fitting the participant’s story into a proposed archetypal framework such as the stages of grief, for example)<sup>7</sup> or removed by editing out the continuity, interconnectedness and temporality of events constructed by the participant in order to feature paradigmatic themes (Polkinghorne 1995:95). Thus what the researcher does with the plot of a narrated research text can be understood as an effect on its narrativity.

## **1.2 Narrative as a system of understanding melanoma patient experience**

The thesis was borne of a personal and professional interest in story plot. It was sparked by identification of the structural similarity between literary, fictional tales of personal journey and autobiographical stories of healthcare experiences. In particular I was taken with the structural similarity between anecdotes of melanoma patient experience gleaned in conversations with family and friends, and the archetypal transformation narrative of personal journey embedded in mythological stories and modern film scripts.<sup>8</sup> In this narrative, protagonists are compelled as a consequence of disruption to leave their ordinary worlds and move through a plot that takes them into a realm of new frontiers where they face physical and psychosocial challenges that inform a transformation so significant as to result in death or alter their way of life forever more.

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<sup>7</sup> I explore this idea in Chapter 5, applying the core plot of the archetypal literary narrative of transformation and personal journey to research data.

<sup>8</sup> I became aware of this archetypal narrative through the work of mythologist Joseph Campbell and film script analyst Christopher Vogler: Campbell, J. (1949/2008). *The Hero With a Thousand Faces*. California, USA, New World Library, Vogler, C. (1998). *The Writer's Journey: Mythic Structure for Writers*.

In my early research for the thesis, I found that sociologist Arthur Frank had made an association between the identity people take on in illness and the identity of the central character in this archetypal literary narrative of transformation and personal journey. He called this narrative the ‘quest’ narrative Frank, A. W. (1997). *The Wounded Storyteller: Body, Illness, and Ethics*, University of Chicago Press. I examine the ideas of these three authors further in Chapter 2.

It seemed to me that this literary plot, which I explore further in Chapters 2, 5 and 8, had metaphoric parallels to the bio-clinical plot people move through as a result of their health condition and also as a result of the experiences they have as patients—when they become, as it were, strangers in a strange land.

In the contemplation of this idea, I had to consider that the enactment of a physical transformation in this archetypal quest narrative is accompanied by transitions in personal identity and existential focus—an ‘inner’ journey that takes place via the ‘outer’ journey. It defined the scope of my interest in relation to this thesis: my primary field of focus is the structure of the outer “eventness”, as Mattingly frames it (Mattingly 1998:8), of patient experience that moves the patient experience from one state of being to another. For patients, experiences of medical care unfold as progressive narratives. Investigating patients’ experiences of care in disparate organisational arenas or in relation to particular phases of disease management brings a critical consciousness to those domains but does not capture the ‘whole plot’. Missing is the progressive portrayal of events and processes that impact and inform patients’ experiences and responses to care. It is through this whole plot perspective that the focus is directed to the patient point-of-view of healthcare experiences as longitudinal narratives that emerge over time. The merit of capturing the whole plot of eventness in melanoma patient experience underpins the interest of this thesis in patient journey meta-narrative.

### **1.3 Thesis context: patient-centred care**

In the wider context beyond melanoma, the investigation of narrative as a system of understanding patient experience has merit because of its implications for the delivery of patient-centred care policies. The core values of patient-centred care are configured around delivery of care that is safe, efficient and personally “meaningful and valuable” (Epstein and Street 2011). These values underpin a goal in patient-centred care of redefining the identity of patienthood from submissive recipient of care to proactive convenor of care (May, Eton et al. 2014). The intention is that people understand healthcare as performing a function in their overall responsibility for their lives. Services are being designed to support patient autonomy, relationships with care providers are being framed as collaborations in shared health management (O’Daniel and Rosenstein 2008, Gardner 2016), and patients are being positioned as protagonists of their own stories, in contrast to the traditional paradigm in which doctors were the heroes of patients’ stories.

This goal is enacted and evaluated diversely within the disassociated ‘sovereign states’ of healthcare systems. These silos of healthcare, fragmented clinical-professional

groupings, hierarchically- and heterarchically-constrained service configurations and poorly connected organisational and institutional enterprises (Braithwaite, Skinner et al. 2011) have their own policies and practices on patient-centred care with varied success in different clinical contexts (Gardner 2016). Consequently, a person who needs to move between services in order to achieve wellness may experience inconsistencies, disparities and lack of patient-centred care in some settings. Patients have to navigate this organisational complexity, and at each stage redefine their identity, re-establish relationships and reframe their experiences in relation to the local enactment of patient-centredness.

The lack of consistency in the delivery of patient-centred care and the ‘backstep’ experiences in which patients are not respected as managers of their own health in particular domains may impact the overall achievement of the goal. Only the patient can identify incremental issues that occur progressively because “the patient is the only person who sees the whole journey. Staff only see the component for which they are responsible, and no single staff member oversees all the steps in a patient’s journey” (Ben-Tovim, Dougherty et al. 2008:S14). Comprehending the successes and failures of patient-centred care in particular domains of care is valuable only if those evaluations are then gathered into a total patient journey framework. Yet there is no global conception that comprehensively represents how patients experience care. Currently the only meta-views of patients’ outset-to-outcome experiences are quantitative patient experience surveys. These offer broad conceptions of trans-system patient satisfaction, which is an evaluation of healthcare provider performance against criteria defined by healthcare services, and is not the same as comprehending the nature of patients’ experiences. Quantitative research on patient experience is also limited in that it largely measures patients’ attitudes to pre-defined questions rather than facilitating their subjective descriptions of on-the-ground experiences.

Inattention to the whole plot of the patient journey meta-narrative diminishes the capacity of the patient-centred paradigm to be self-reflective—to identify where it is going right and wrong in addressing “the dynamics of balancing the biomedical model with the bio-psychosocial model, and balancing the acute care models with chronic care and community oriented patient centred models” (Martin, Biswas et al. 2014:2). Patient-centred care can thus be conceived of as under-theorised in relation to the overarching experience of being a patient, and under-connected to the goals of its own paradigm. The impact of this is apparent in the “failure to translate research into policy and practice” (Grimshaw, Eccles et al. 2012:1). A tremendous amount of patient experience data is now generated but there is no centralising theory or mechanism for reconciling

findings and filling in gaps so that data can be used for trans-system quality improvement (Coulter and Locock 2014). A meta-narrative perspective may facilitate healthcare designers and policy-makers to look beyond local, disparate enactment and evaluation of patient-centred care to a patient-centred perspective across a care trajectory.

#### **1.4 Thesis context: the challenge of patient perspective**

When people with illness enter the world of healthcare, the narration of their stories becomes a group activity. Clinicians inform the plotlines of the stories by advising and deciding on courses of action, and they narrate patients' stories from their perspectives in clinical notes and referrals between services. Healthcare institutions stipulate place and time, and format the stories into patient charts and administrative documents. Government healthcare policy-makers underwrite the outcome of patients' stories with funding decisions and approvals on medications, clinical trials and medical insurance. Patients' stories are written in multiple ways from multiple points of view. In this milieu, patients' own perspectives on what is happening to them become just one of many perspectives, and in some circumstances, the least highly regarded, most particularly in healthcare settings that are provider-dominated, under-resourced, organisationally dense or economically rationalised (Rooshenas, Owen-Smith et al. 2015). In those circumstances, the healthcare narrative of patient-centred care defaults to its traditional biomedical perspective. The treatment of the disease is privileged over collaboration with the patient to meet his or her bio-psychosocial-medical needs.

Even in the 'ordinary' healthcare settings of wealthy countries, socio-economic-political pressures subjugate the patient-centred perspective on how care should be delivered. Medical practitioners and ancillary healthcare providers struggle to provide co-ordinated care (Jones, Vu et al. 2015) and have to balance the needs of patients with the requirements of government and institutional policies (Goodrich and Cornwell 2008, Barker, Kumar et al. 2011) that define resource availability and shape fees for services. Patients are forced to accept long waiting times for consultation appointments (Hewitt, McCloughan et al. 2009, Moffat, Hinchliffe et al. 2016), staffing varies in quality and quantity (Clarke and Donaldson 2008, Griffiths, Ball et al. 2016) and the dynamics of supply and delivery of healthcare impact the costs of services and health insurance (Feldstein 2012:178/266, Karanikolos, Mladovsky et al. 2013) that are passed on to patients.

Further, entrenched practices and customs diminish the patient perspective in relationships with healthcare providers. Condescending behaviours by clinicians are still

reported (Frosch, May et al. 2012, Ruberton, Huynh et al. 2016). Clinic receptionists are still experienced as ‘gatekeepers’ who can be difficult to communicate with (Andersen and Vedsted 2015). Patients are still frustrated by waiting times in emergency and out-patient clinics, despite the availability of relevant technology to improve the experience (Dixon and Prior).

Additionally, paradoxically, the disparity of expertise between patients and clinicians challenges the priority of the patient perspective. The information asymmetry problem (Mooney & Ryan, 1993) puts clinicians in the ‘power seat’; their perspectives on patients’ biomedical needs are framed by training, knowledge, skills and experience that patients do not have. The balancing of clinical perspectives with patients’ psychosocial needs is a complex undertaking (Halpern 2003). Beyond these personal relationships, intrinsic processes of medicine, such as technology that identifies disease where no symptoms are apparent, dissipate the patient perspective of control over one’s own body.

Thus on entering the realm of healthcare, the patient’s perspective becomes subject to the policies, practices, idiosyncrasies and authority of other people and the organisations they serve. The patient’s story may be deconstructed into paperwork and subsumed by conventional practices (Wald 2016); it becomes difficult for patients and healthcare providers to determine whose perspective is to be prioritised. Using narratological precepts to conceive of patient experience, the many perspectives that are enacted in healthcare can be made explicit, and the patient perspective can be made unambiguous. By these precepts, the representation of patient experience has a narrator; the narration is autobiographical or biographical; there is a ‘central character’; there are secondary characters; and there is a subjectively emplotted beginning, middle and end of the experience.

The context for the thesis is thus threefold: the burden of melanoma on people and healthcare systems; the need for a centralising theory of patient trajectory that facilitates the translation of patient experience data into patient-centred policy; and the blurring of patient perspective among the many perspectives on patient experience in the healthcare milieu.

## **1.5 Aims and design of the study**

At the conceptual crux of the meta-narrative approach to patient experience is an interdisciplinary fusion of narratological scholarship, qualitative research methodology and healthcare research. Working in that liminal space, I set out to address a primary

research question: *‘How can I investigate and represent the healthcare experiences of people with melanoma to facilitate meta-narrative views of their patient journeys?’*

Within the context of this primary research question, I set out also to answer two radial questions. The first pertained to the experiential content of research data: *‘What personal experiences of healthcare are meaningful to people with melanoma throughout their patient journeys?’* The second question focused on the correspondence between narrative structures and the structures of patient experience: *‘What extant plots and literary devices are and can be used to identify and represent melanoma patients’ longitudinal experiences of care?’*

In posing differing approaches to the one topic of interest, these questions presented a case for a triangulated study (Annells 2006:56, Bamberg 2012:37). The narrative epistemology of the research suggested that in addition to exploring different modes of narrative-based inquiry and narrative analysis of data in order to facilitate meta-narrative views of melanoma patient journeys, different sources of narrative data on melanoma patient experience might also be investigated. To focus the “different inquiry components” (Creswell and Clark 2011:62) of the study, I set out three objectives:

**Objective 1:** To identify collective experiences of melanoma care—including met and unmet needs—grounded in ethnographic data.

**Objective 2:** To identify collective experiences of melanoma care—including met and unmet needs—grounded in written, autobiographical data.

**Objective 3:** To identify the socially and culturally shared narrative means by which the care experiences of people with melanoma can be, and are, represented.

To respond to these questions and objectives, I designed a study comprising four projects, involving two study populations. The first study population included seven Australian adults, aged 25 to 85 years old, with advanced stage melanoma and metastatic cancer. The participants were recruited from the oncology unit of a large public Australian hospital. I spent six months immersed in the outset-to-outcome journeys of these people. I observed and interviewed them to understand the events and experiences of their bio-clinical plots and to comprehend their unique and shared perspectives on those events and experiences. I conducted two analyses of the data produced from this investigation in order to respond to the primary and sub-questions and objectives of the research. In a first analysis I used a conventional grounded approach to comprehend content themes in the data. In a second analysis, I examined the relevance of a top-down approach in which I mapped the plot structure of the archetypal narrative of personal journey to the structure of patient experience



represented in the data.

The second study population was made up of 214 autobiographical accounts written by people with melanoma, whose ages appeared to range from 18 to 85<sup>9</sup>. Again I conducted two analyses of the data produced from these stories: a grounded approach in which themes emergent from the data were drawn into categories and an analysis of the narratological heuristics that facilitated these authors to convey their experiences of melanoma care.

## **1.6 Broad aims of the study**

The wider aims of the study have to do with affiliation for the complex nature of being a melanoma patient. I set out with this study to honour melanoma patients' stories of their healthcare experiences, firstly by investigating them. Changes in the way researchers approached investigations of patients' experiences were brought about by the shift towards narrative that began in the 1970s. The move away from logico-scientific modes of thinking about evidence of experience to "narrative ways of knowing" (Bruner 1988/2004) constituted a paradigm shift in beliefs about 'experiential evidence'. Researchers became increasingly attracted to, and contemplative about, narrative methodologies. They continue to be engaged in wide-ranging and conceptually complex debates about what 'narrative' means, how it should be used in interaction with research participants and how to approach the analysis of narrative data. Now the lively discourse about narrative as a system for comprehending patient experience functions as both a clarifying and confusating force for those of us working in that realm of qualitative research. I hope to shed light on useful innovative interpretive frameworks for conceptualising narrative methodology.

I set out also to honour patients' experiences by producing findings that can be used to reflect on the kinds of experiences that are offered to melanoma patients. Scholarly attention is being paid to narrative knowledge of patient experience as a resonant platform for policy and practice enhancement (Coulter and Locock 2014); to that end, diverse avenues of narrative knowledge are being explored. The Health Experiences Group based at Oxford University in the United Kingdom, for example, has added filmed patient experience interviews and dramatic re-enactments of issues in illness and patienthood to its archive of patient experience data. The Narrative Medicine program at Columbia University Medical Center in the United States, as a contrasting example, uses literary analysis, literary texts and creative forms of expression to engage

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<sup>9</sup> The demographic characteristics of the storytellers could not be consistently determined.

healthcare providers with the skills required for “narrative competence” (Charon 2007) in listening to patients’ stories. My goal is that this triangulated study will make a contribution to the diverse forms of narrative knowledge that are informing policy and practice.

Finally, I mean with this thesis to honour patients’ experiences by attending to the new mediums through which patients tell their stories—the social media, the blogs and the personal accounts posted to patient support websites (O'Brien and Clark 2010, Mazanderani and Powell 2013). There is no doubt now that a qualitative evidence base makes an important complementary contribution to quantitative data in facilitating patient-centred, satisfactory care (Curry, Nembhard et al. 2009). There are concerns, however, about digital technologies as legitimate sources of data and as fields for ethnographic research. Issues are raised about the quality and ethical management of data, or alternatively there is a “sidestepping of digital methods” (Murthy 2008:838) by social researchers. I engage with these realms of research through the exploration of patient stories published to the Internet.

### **1.7 An autoethnographic note**

As Fox et al. note, research involving people with melanoma in late or critical stages of disease requires an approach cognisant of the “unwell, emotionally fragile, and fatigued” (Fox, Windsor et al. 2016:261) state of the participants. As an ethnographic researcher, I understood that I would be observing people in some of the most distressing and decisive circumstances of their lives, and asking them to be descriptive, reflective and open in their communication with a stranger. In order to prepare for this relationship with participants, I looked to the socio-narratological constructionist idea of critical and chronic illness as a biographical disruption (Bury 1982) to a lifeworld (Mishler 1984:182). Working in this paradigm, Frank proposed the narrative identity of patient as ‘wounded storyteller’(Frank 1997:98)—a person whose illness has wreaked havoc on the stability of plans for the immediate and imagined long-term future, who can no longer confidently tell the story of self. In light of this concept of narrative chaos in the ethnographic setting, I looked to the order represented by bio-clinical plot. With information from the participants’ oncologist, who was my site supervisor, combined with information gleaned from participants themselves in the first meeting I had with each of them, I mapped out the medical consultations, tests, therapies, palliative measures and other events and processes they had been through and charted what they had thought and felt about those circumstances. I used these points as markers to initiate

discussion in those times when discussion on other topics was difficult for the participants.

The biomedical plot also became a steadying mechanism for me in emotionally heightened situations with participants, and most particularly with two participants who died within six weeks of taking part in the study. I had prepared myself in the lead-up to the research to be in emotively charged situations talking with people and their families who were in highly challenged circumstances. I had discussed potential scenarios with my academic supervisor, and together we had strategised a support plan utilising resources from the research institute within which my postgraduate work is situated, and resources available within my university. Beyond this, I am an experienced interviewer with a significant personal support base in family and friends. Still I found it deeply moving to be with these participants.

I was deeply engaged also with the melanoma patients who represented themselves on the Internet through their illness narratives. They claim their pathographies as personally therapeutic and they speak to their unseen audiences in ways that are informative, supportive, provocative, persuasive and emotive. With the multiple readings required for meta-analysis, I became embroiled in the details of the stories these people told. I found that my imagined conceptions of how they looked and spoke, and my curiosity about what had happened to them since they published their stories, resonated long after the study was complete.

### **1.8 The conceptual scope of the thesis**

I include a discussion on semantic concepts in this section because there is nothing so easy as a set of simple definitions in this multi-disciplinary domain. Rather, “scholars from different disciplines distinguish between theories and conceptual models in contrasting ways” (Coreil 2009:69). The intention is not to resolve these long-debated semantic issues but to acknowledge them and move them to a functional place in the thesis. In some of the concept discussion that follows I use a contrasting frame of reference to consider ambiguities.

#### **‘Narrative’ and ‘story’**

‘Narrative’ and ‘story’ are used interchangeably in both grey and academic literature. Wikan offers a differentiation when she conceives of narrative as a scholarly framing of story: “People bleed stories, but academics gather narratives” (Mattingly and Garro 2000:217). However as Woods notes, in general there is not only a “difficulty of giving precise definitions of narrative” but also “the reluctance of many to do so” (Woods

2011). Given the absence of boundaries that separate the meaning of these terms (Andrews, Squire et al. 2008:1), I conceptualise the terms as being at once inextricably linked, but also constituting functional similarities and differences. The etymology of each offers some distinction: ‘Narrative’ has its source in phrases meaning ‘telling a story’ and ‘suited to narration’. In this conception, ‘narrative’ refers to the thought processes and act of performance. ‘Story’ has its source in words related to ‘history’, ‘chronicle’ and ‘account’. ‘Story’ thus refers to an artefact produced by narrative processes (Meister 2014:12), in which experience is emplotted and assigned meaning. ‘A narrative’ has the same properties as ‘a story’ and both are used to categorise groups of stories that may each have unique forms of expression but which have common themes, for example ‘quest stories/quest narratives’. In this sense, however, as Hyvärinen notes, ‘narrative’ can also be used to denote a “general assumption, theory, or ideological stance without temporal organization” (Hyvärinen 2008:448), for example ‘a corporate narrative’, and in this way narrative has a different meaning from story. As a general attempt to provide some scope to each term, I use ‘story’ to mean a verbal or written text with a temporally located plot that represents an individual’s experience, and ‘narrative’ to mean both the cognitive act by which we represent experience, and a collective storying of experience. This adheres to some degree to the differentiation described by Connelly and Clandinin in relation to the research process of narrative inquiry, in which they point to the “reasonably well-established device of calling the phenomenon ‘story’ and the process of inquiry ‘narrative’” (Connelly and Clandinin 1990:2).

### **Patient experience**

In defining the scope of this thesis I looked to the literature to understand what aspects of a person’s experience would be attributable to ‘patient experience’ and what would lie outside those boundaries. I found there is confusion in the definition of patient experience, a meagre amount of scholarly consensus (Wolf, Niederhauser et al. 2014) and a tendency to rely on implicit definitions framed by one or all of the dictionary meanings, which are, in order to be explicit, provided here (Macquarie 2016):

- a particular instance of personally encountering or undergoing something
- the process or fact of personally observing, encountering, or undergoing something
- the observing, encountering, or undergoing of things generally as they occur in the course of time
- knowledge or practical wisdom gained from what one has observed, encountered, or undergone

- the totality of the cognitions given by perception; all that is perceived, understood, and remembered.

### **Patient satisfaction and patient experience**

The concept of ‘experience’ that underlies patient experience research shapes the goals of data collection and data analysis. It determines, for example, whether the gathering of qualitative experiential data is a means of evaluating patient experience against a particular benchmark or set of criteria, or a means of comprehending what patients want to tell of their experiences. I resolve the differences between the two as a typology.

‘Evaluative narrative inquiry’ is concerned with patient satisfaction; it attends to patients’ experiences of something—staff, a service within an organisation, a setting such as a waiting room or a diagnostic imaging room, or an entire organisation such as a hospital or palliative care centre. It may seek out the ‘small stories’ (Georgakopoulou 2007:20) that take place in these domains however its focus is on framing patient experience data as opinion. In contrast, ‘biographical narrative inquiry’ is interested in patients’ subjective emplotment of their experiences. It attends to patients’ assignation of personal meaning through the narration of the thoughts and feelings that are, or retrospectively were, attendant to their experiences (Greenhalgh and Hurwitz 1999).

Both endeavours engage with narrative sources of data and narrative methods of data collection and analysis in order to seek out the patient perspective. Both endeavours may explore patient experience in the context of an overarching agenda for prediction and control (Bamberg and Georgakopoulou 2008), in support of improvements in policy and practice. However, the epistemological commitment of the present study is to biographical narrative inquiry. The merging of the two may occur inasmuch as study participants choose to express satisfaction or dissatisfaction with an experience.

### **Patient experience and illness experience**

Perhaps as a consequence of issues with the definition of patient experience, there is a lack of differentiation in the literature between patient experience as experience resulting from interactions with healthcare services and providers, and illness experience as experience resulting from ‘having’ an illness. Though the two are inextricably linked ontologically, the primary investigative interest of the present study is the narrative expression of melanoma patients’ experiences of healthcare, and their reflections and responses to those experiences. The study engages with, but does not seek out, a comprehension of the phenomenological impact of the disease.

## **1.9 Organisation of the thesis**

The intention is that the conceptual and empirical knowledge gathered in this thesis is a basis for a first conversation about longitudinal narrative frameworks for comprehending melanoma patient experience—meta-narratives of patient journey. I perceive the responders and audiences to the conversation to be not only the examiners but also qualitative researchers involved in patient experience studies, practitioners involved in the care of people with melanoma, patient-centred care policy-makers and patients themselves. To rightfully engage in such a conversation, I investigated in the next chapter the breadth of melanoma patient experience research to date, and the precepts of narrative that are relevant to the study. In the chapters that follow, I present four papers currently under review for publication in international peer-reviewed journals. These papers represent the empirical and meta-analytic findings of the four research projects that comprise the study. A fifth paper, which has been published in an international peer-reviewed journal, presents a conceptual normative model to assist patients in emplotting their healthcare experiences. Each of these chapters is presented as a journal article, and so each one is characterised by a framing of the topic in the literature, a summarised discussion of the research design, a set of findings and a discussion and conclusion. The thesis closes with a discussion of the findings of the present study, including a consideration of the ways in which the research has responded to the literature review and conclusions with regards to the opportunities enabled by this research. The organisation of the thesis is detailed in Table 1 and described as follows:

### **Chapter 2**

The review of literature in this chapter is organised in two parts: i) a review of the breadth of qualitative research on patient experience in melanoma care; ii) a review of scholarly discourse related to narrative modes of investigation and patient experience.

### **Chapter 3**

While each paper comprises a section on the methods used in data collection and analysis, this chapter identifies in greater detail the concepts and methodology that underpinned the ethnographic research project.

### **Chapters 4 and 5**

In these chapters, I present the papers resulting from the ethnographic research project.

The data collected in these projects reflect the unfolding meta-narratives of these people's collective journeys, starting from the varying health issues that compelled them to seek medical advice, moving through their experiences of medical and ancillary care and progressing to treatment, management of their tumours, or as noted earlier, death. Two papers were produced from this research project: one was co-authored with my PhD supervisor and my site supervisor and another was co-authored with my supervisor.

## **Chapters 6 and 7**

In these chapters, I present the papers resulting from the analysis of 214 illness narratives written by people who had experienced, or were still experiencing at the time of their writing, medical management and the receipt of healthcare services for melanoma. These accounts described the events of narratives that often began even before symptom identification—when sunbaking was a childhood delight and a ruined future from skin cancer was unimaginable—and went through to the collateral damage of surgeries and the lifelong healthcare needs that defined these storytellers' lives. Two papers were produced from this research project: both were co-authored with my PhD supervisor.

## **Chapter 8**

Patients are untrained in how to protract patient-centred care from healthcare services while also managing the myriad challenges they face as they progress from illness and diagnosis through treatment and into the terrain of outcome. In Chapter 8 I present a paper co-authored with my supervisor in which the plot of the archetypal literary narrative of personal journey is explored as a narrative structure patients can adapt to the representation of their experiences.

## **Chapter 9**

The conclusion discusses the aggregate findings of the papers and examines how these findings map to the opportunities identified in the literature review, and to the overall objectives of the thesis.

**Table 1:** Organisation of the thesis

Purpose of chapter	Methods	Participants	Thesis Chapter
To introduce the thesis; to explain how narrative as a system of understanding and representing longitudinal patient experience might be of service to melanoma patient research; and to establish the	Discussion		<u>Chapter 1:</u> Introduction

aims and broad design features of the study.			
To identify existing qualitative studies that have used narrative modes of inquiry to comprehend and represent the healthcare experiences of melanoma patients; to identify the historical and current conceptual approaches to narrative as a system of understanding patient experience and patient journey.	Review of studies; review of key concepts		<u>Chapter 2:</u> Literature review
To consider relevant precepts and establish a methodology for the ethnographic investigation of melanoma patients' healthcare experiences from symptom identification to health outcome.	Identification and discussion of relevant methodologies		<u>Chapter 3:</u> Methodology
To identify progressive experiential phases of the melanoma patient journey using data from an ethnographic study of people with advanced stage and metastatic melanoma as they moved from symptom identification to health outcome.	Ethnography, narrative interview, thematic analysis	Seven people aged between 25 and 85	<u>Chapter 4:</u> Lamprell, K. Braithwaite, J. Chin, M.
To explore the relevance of an archetypal narrative plot to the experiential phases of people with advanced stage and metastatic melanoma as they moved from symptom identification to health outcome.	Literary analysis	As above	<u>Chapter 5:</u> Lamprell, K. Braithwaite, J. Chin, M.
To identify progressive experiential phases of the melanoma patient journey using data from a meta-analytic study of autobiographical accounts written by people with melanoma.	Thematic analysis, quantitative analysis	214 autobiographical accounts published on melanoma support websites in four countries	<u>Chapter 6:</u> Lamprell, K. Braithwaite, J.
To identify the extant plots and literary devices that people with melanoma use to describe their healthcare experiences in written personal accounts.	Literary analysis	As above	<u>Chapter 7:</u> Lamprell, K. Braithwaite, J.
To explore the relevance of a literary plot structure as a model for use by patients in representing their longitudinal healthcare experiences	Concept discussion		<u>Chapter 8:</u> Lamprell, K. Braithwaite, J.
To identify the findings of the present study; to synthesise the findings with findings from existing studies; to draw conclusions about narrative modes of inquiry into, and meta-narrative modes of representing, longitudinal melanoma patient experiences.	Discussion		<u>Chapter 9:</u> Discussion and conclusion

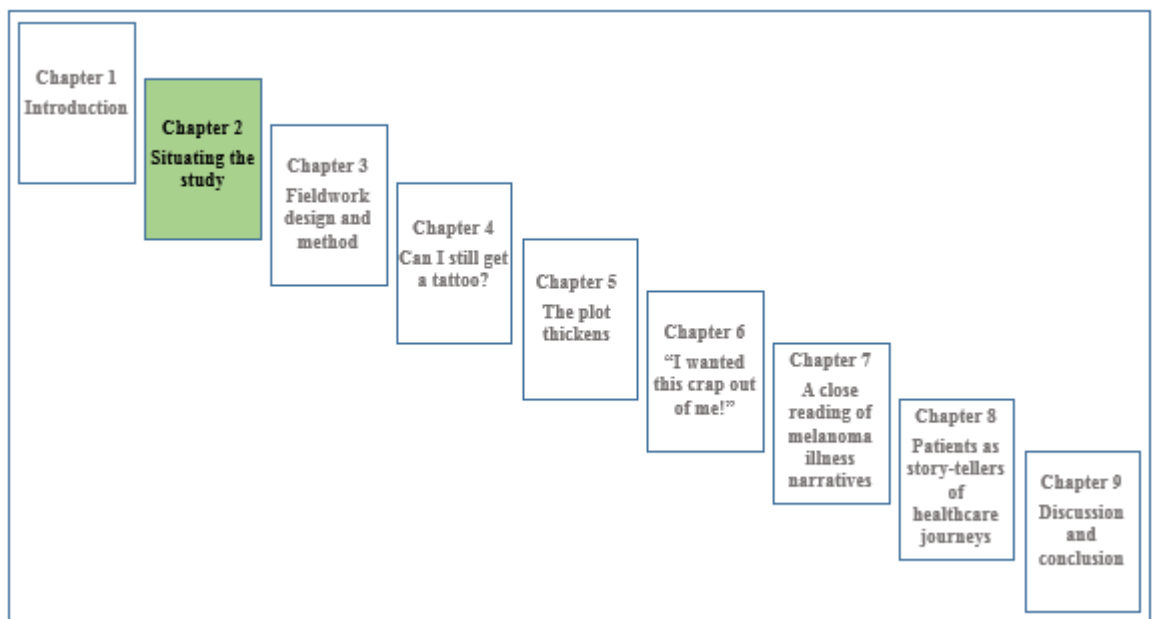
### 1.10 Summary: Distinguishing elements of the study

Patient experience is the phenomenon of interest to this thesis, melanoma care is the study domain (Coreil 2009:69) and exploring narrative as a system for understanding the melanoma patient journey is the aim. Firstly, the study responds to gaps in qualitative patient experience research related to melanoma. In attending to outset-to-outcome meta-narratives of melanoma patient experience, the study contributes qualitative knowledge to a medical arena that is in need of information about the longitudinal burden of patient care. Secondly, the study makes a cross-disciplinary



contribution to qualitative research methodology. The study brings an innovative and comprehensive, triangulated approach to qualitative data collection and data analysis with its collection of data from two distinct sources and its analyses based on a grounded thematic approach as well as a top-down narratological analytic framework. Finally, the patient journey methods developed in the study support the gathering of trans-system knowledge about patient experience, which is germane to the improvement of patient-centred policy and practice, and which, in turn, will enhance the healthcare experiences of people with melanoma.

## 2 Situating the study



In this section I situate the aim of the thesis in context to the current body of work in this arena. I identify and consider two lineages, on which basis I produce two reviews of literature.

**1 Melanoma patient experience in the literature.** This review identifies existing primary qualitative studies on the healthcare experiences of melanoma patients as perceived by people with melanoma. The review analyses the findings of those studies in order to establish a platform of existing qualitative knowledge about melanoma patients' experiences of healthcare, and also to comprehend the narrative and meta-narrative methodologies of those studies in relation to the melanoma patient journey. This is a meta-ethnographic review (Noblit and Hare 1988) in that it accounts for the way that the findings of existing qualitative studies form a whole view (Barnett-Page and Thomas 2009:3) of what is known about melanoma patients' experiences of care. The review conceives of gaps and opportunities (Cronin, Ryan et al. 2008) for the present study.

**2 Foundation concepts (Hart 1998:7)** relating to narrative modes of identifying and representing patients' longitudinal experiences of healthcare. This review comprehends the intersection of narrative inquiry in social science, narrative as a means of comprehending and articulating human experience and patient experience research. In particular the review takes into account ontological foundations of narrative as a process and an artefact, narrative epistemology in data collection and analysis, and new analytic modes in relation to autobiographical narratives of illness and patienthood. The review process snowballs seminal sources (Greenhalgh, Robert et al. 2005:421) to arrive at a

profile of the relevant foundation concepts that will inform the approach to the present study. The report of this review is reflective and interpretive (Baumeister and Leary 1997:312), and its format is discursive (King and He 2005, Booth, Rees et al. 2010).

### Sources of literature

In each of the two reviews, I investigated the academic sources listed in Table 2. Additionally I looked on the search engine Google Scholar for broad sweeps of the literature on ad hoc topics.

**Table 2:** Academic databases used as sources for the literature reviews

DATABASES	DESCRIPTION
Scopus	A citation index covering literature in the fields of science, technology, medicine, social sciences and arts and humanities. Maintained by Elsevier.
PubMed	A database of literature abstracts and citations in the fields of medicine, nursing, dentistry, veterinary science, healthcare, preclinical and life sciences. Maintained by the U.S. Government National Library of Medicine.
CINAHL (Cumulative Index to Nursing and Allied Health Literature)	A database of literature abstracts and citations in the fields of nursing, biomedicine, health sciences librarianship, alternative/complementary medicine, consumer health and allied health disciplines. Maintained by EBSCO Information Services.
Sociological Abstracts	A database of literature abstracts and citations in the fields of sociology and allied behavioural disciplines. Maintained by ProQuest.
PSYCHINFO (Psychological literature)	A database of literature abstracts and citations in the fields of behavioural sciences and mental health, and allied topics in other fields. Maintained by the American Psychological Association.
Web of Science	A citation index covering literature in the fields of science, social sciences, arts and humanities, and chemical sciences. Maintained by Thomson Reuters.

## 2.1 Melanoma patient experience in the literature

As noted in Chapter 1, the need for investigation into the care experiences of melanoma patients as a discrete population of cancer patients is intensifying with the rising incidence of the disease. Melanoma makes significant demands on people and health systems (Cornish, Holterhues et al. 2009, Joshua 2012), requiring long-term disease surveillance and psychosocial management (Kasparian, McLoone et al. 2009). This review locates the qualitative studies from the past ten years that have investigated melanoma patients' experiences of care from the perspectives of people with melanoma.

## 2.2 Literature review methodology and method

The overarching methodology for this review is that of meta-ethnography: it establishes a collective set of existing qualitative studies into melanoma patients' care experiences from the perspective of melanoma patients, and also accounts for the way that these studies reflect a whole view of melanoma patient experience. The review is therefore "interpretative rather than aggregative" (Noblit and Hare 1988:11). The whole view of patient experience that the review reflects is meta-narrative (Greenhalgh, Robert et al. 2005), identifying the storyline of patient journey that is established by this body of work.

The method for the review has been selected from the typology of strategies for literature reviews established by Onwuegbuzie et al. (Onwuegbuzie, Leech et al. 2012:10) and has been adapted to the interests of the present review. The strategy is represented in Figure 1. In this analytic and interpretive framework, the following criteria have been taken into consideration:

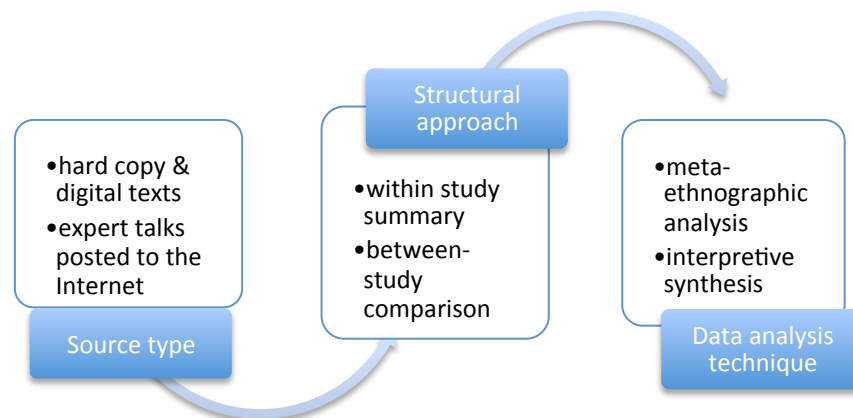
- Source type. Literature deemed worthy of academic review has long been established as that produced by "researchers, scholars, and practitioners" (Fink 2010:2), however given the interdisciplinary and liminal spaces that these professions now enter in their exploration of phenomena, the style and format of literature for review may include talk, observations, drawings/photographs/videos and documents. This review includes written documents in hard copy and digital media formats, and the observation of expert talks posted to the Internet<sup>10</sup>.
- Structural approach. This review undertook a within-study summary of the contents of each work and a between-study analysis that linked together multiple works by means of comparison and contrast.

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<sup>10</sup> In particular, TED talks on healthcare (<https://www.ted.com/topics/health+care>) and TEDMED talks (<http://www.tedmed.com/videos-info>).

- **Data analysis technique.** As noted, this review employs a meta-ethnographic approach to analysis, which is an approach devised by Noblit and Hare that views a field of literature as a culture of knowledge within which are domains of subcultures (Spradley 1979). The meta-ethnographic approach was selected for the present study because of the disparate and incomparable methods and findings in the literature and because it relates to the intent of the review—to interpret the culture of knowledge established in existing studies in the context of a meta-narrative view of patient journey.

**Figure 1:** Method for the review of qualitative studies investigating the healthcare experiences of people with melanoma



## Objectives

The objective of this review is to establish a profile of existing qualitative knowledge about melanoma patients' subjective experiences of healthcare from symptom identification through to outcome, and to establish a knowledge base about the use of narrative and meta-narrative approaches to qualitative studies of melanoma patient experience. The findings of the review inform the design of the present study and provide a means by which to assess the contribution of the research.

Four questions guided the review:

1. What qualitative studies have investigated melanoma patient experience from patients' points of view?
2. What knowledge of melanoma patients' perceptions of healthcare do these studies contribute?
3. What narrative methods have these studies employed?
4. What, if any, meta-narrative methods have these studies employed?

## Scope of the review

**Research topics:** The studies of interest to this review comprise qualitative data on the biomedical, psychosocial and logistical experiences of people with melanoma that arise as a direct result of their experiences related to medical care and the actions of health providers. Studies of patients' pathways from symptom identification to medical care were included on the basis that they represent subjective negotiated entries into healthcare experiences. Studies of patient perspectives on particular care events and phases of disease management were excluded if the focus was solely on existential perceptions of the impact of illness or on patients' lifeworlds outside of healthcare-related domains, such as the impact of having melanoma on relationships (see, for example, Drabe, Jenewein et al. 2016, Engeli, Moergeli et al. 2016). Studies were also excluded if they specifically focused on patients' satisfaction with particular healthcare services, or on patients' adherence to and opinions of self-monitoring skin assessment programs (see, for example, Korner, Drapeau et al. 2013, Hall and Murchie 2014, Secker, Bergman et al. 2016) and patients' behaviours in regards to lifestyle and management of sun exposure (see, for example, Oliveria, Shuk et al. 2013).

**Method and methodology:** The studies of interest to this review were those that comprise narrative data collection methodologies and methods such as ethnography and narrative interview, and those that employ meta-narrative approaches to contextualising research findings in relation to the melanoma patient journey. The review included only studies of people with melanoma; it excluded mixed study populations comprising both people with melanoma and those with non-malignant skin cancer (see, for example, Lee, Klassen et al. 2016) or people with melanoma and their carers or other non-patients (see, for example, Tan, Butow et al. 2014).

The criteria for inclusion and exclusion are categorised in Table 3.

**Table 3:** Scope of review of qualitative studies

<b>FILTER</b>	<b>INCLUSION</b>	<b>EXCLUSION</b>
<b>Date limits</b>	Up to ten years prior to November 1, 2016	More than ten years prior to, or published after, November 1, 2016
<b>Population</b>	English-speaking people over the age of 18 years diagnosed with melanoma, at any stage of the disease	People who have not been diagnosed with melanoma; mixed population studies
<b>Method</b>	Qualitative, narrative, investigates patient experience from perspective of people with melanoma	Quantitative, non-narrative, investigates melanoma patient experience from perspective of healthcare providers and non-patients
<b>Research subject</b>	Patients' perspectives on: <ul style="list-style-type: none"><li>• symptom identification</li><li>• lead-up to diagnosis</li><li>• diagnosis to outcome and follow-up care</li></ul>	Patients' perspectives on: <ul style="list-style-type: none"><li>• the impact of illness on non healthcare-related lifeworlds</li><li>• satisfaction with specific/trial programs and services</li><li>• melanoma awareness education programs</li></ul>

<b>Search terms</b>	melanoma, patient, journey, experience, narrative, qualitative	
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## **Review strategy**

The identification of relevant data was conducted in two phases. The first phase was intended as an awareness-building exercise in identifying all primary studies in the past ten years that have investigated melanoma patient experience from the perspective of melanoma patients. This phase included studies using mixed collection methods, such as surveys and questionnaires that comprised both quantitative and qualitative research questions. The second phase comprised the review; it distinguished the qualitative from the non-qualitative studies and involved the meta-ethnographic analysis of those qualitative studies that met the criteria.

In detail the review strategy was to:

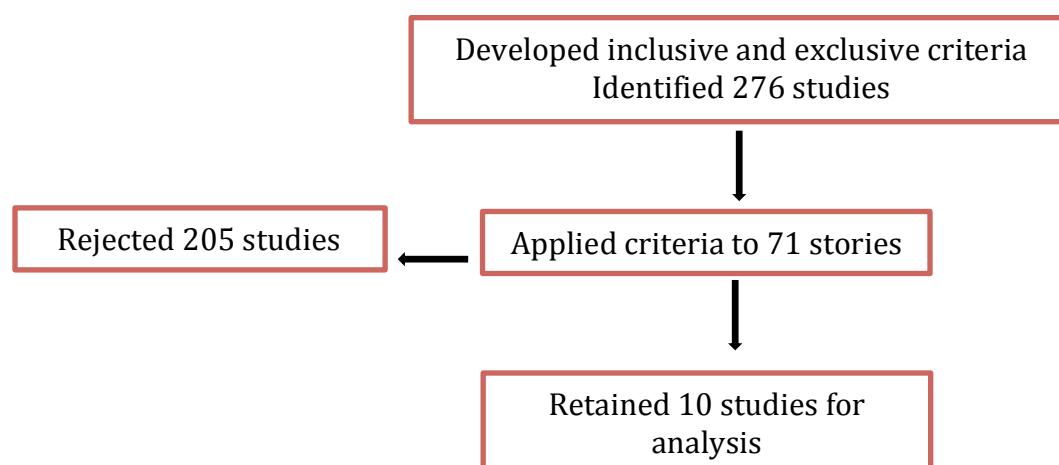
- identify topics of relevant studies
- summarise the findings and methods of each study
- analyse and synthesise the findings to formulate a taxonomy of domains based on progression through the patient journey
- draw conclusions about gaps and opportunities in the literature that would have relevance to the present study.

## **2.3 Literature review results**

### **Selection**

The review identified 276 publications that potentially met the search criteria. Of those, 205 were rejected on title and abstract as being ineligible. A skim-read through 71 studies provided affiliation with the breadth of literature and resolved in the identification of ten qualitative studies that met the criteria. This search is represented in Figure 2.

**Figure 2:** Flow chart for literature search



### Topics of interest in the literature

The studies selected for review are presented in Table 4. The ten studies comprise five main areas of interest relating to particular phases in the melanoma patient journey or relating to issues throughout the patient journey, from diagnosis through outcome and into the follow-up period and recurrence.

**Table 4:** Topics of interest in the literature

RESEARCH FOCUS	STUDY
<b>Pathways to diagnosis</b>	4 studies: (Hajdarevic, Hörnsten et al. 2010, Hajdarevic, Schmitt-Egenolf et al. 2011, Topping, Nkosana-Nyawata et al. 2013, Walter, Birt et al. 2014)
<b>Impact of prognosis</b>	1 study: (Hope-Stone, Brown et al. 2015)
<b>Follow-up care</b>	1 study: (Morton, Rychetnik et al. 2013)
<b>Recurrence</b>	1 study: (Stothers and McCaughan 2015)
<b>Outset-to-outcome</b>	3 studies: (McLoone, Watts et al. 2012, Bird, Coleman et al. 2015, Stamataki, Brunton et al. 2015)

The final selection reflects varying concentrations of interest in particular areas of the melanoma patient journey. Pathways to diagnosis—the period between symptom identification and clinical presentation of symptoms—received the most attention, with four studies focused on this subject and aspects of this subject also explored in studies that investigated the outset-to-outcome experiences of people with melanoma. The topics of interest featured in these studies include: a conceptualisation of archetypal personal decision-making processes during that period (Hajdarevic, Hörnsten et al. 2010); gender differences in decision-making in that period (Hajdarevic, Schmitt-Egenolf et al. 2011); the amount of time that lapses between symptom identification and clinical presentation relative to advanced and less advanced stages of melanomas



(Topping, Nkosana-Nyawata et al. 2013, Walter, Birt et al. 2014); and choice-making in regards to fast and delayed responses to symptoms and how the decisions of physicians led to delays (Topping, Nkosana-Nyawata et al. 2013, Walter, Birt et al. 2014).

One study investigated patients' responses to prognostic information, focusing specifically on people with uveal<sup>11</sup> melanoma (Hope-Stone, Brown et al. 2015). The topics of interest in this study included whether prognostication resolved or engendered uncertainty about the future and how participants in different risk groups responded to their prognosis.

None of the studies focused solely on experiences related to treatment, however the outset-to-outcome studies included topics related to the psychosocial impact of treatment. Bird et al. focused on how treatment impacted levels of anxiety caused by diagnosis (Bird, Coleman et al. 2015:941). McLoone et al. examined how participants at high risk of melanoma recurrence perceived side effects of treatment and the impact of scarring from surgery (McLoone, Watts et al. 2012:1107-8). Stamataki et al. looked at the body image of participants in relation to scarring and lymphoedema.

Follow-up care received singular attention in one study (Morton, Rychetnik et al. 2013)<sup>12</sup> with particular focus on follow-up for people with localised cutaneous melanoma. The topics of interest in that study related to melanoma patients' perceptions of benefits and downsides of follow-up care. Follow-up care also featured in the outset-to-outcome studies, with Bird et al. examining follow-up care in relation to participants' levels of depression and anxiety (Bird, Coleman et al. 2015), McLoone et al. focusing on the role of follow-up clinical skin examinations in psychological adjustment to being at high risk of recurrence (McLoone, Watts et al. 2012) and Stamataki et al. investigating participants' needs for follow-up emotional support related to post-treatment symptoms of lymphoedema, pain and fatigue (Stamataki, Brunton et al. 2015).

One study investigated recurrence of melanoma, focusing specifically on nodal relapse of melanoma<sup>13</sup> (Stothers and McCaughan 2015). The focus of that study was the

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<sup>11</sup> Uveal melanoma is a cancer of the eye.

<sup>12</sup> During the literature selection process, two further studies were identified that investigated follow-up care however neither met the criteria for selection as they explored patient satisfaction with particular follow-up services. The studies were: Murchie, P., E. K. Delaney, N. C. Campbell and P. C. Hannaford (2010). "GP-led melanoma follow-up: views and feelings of patient recipients." *Support Care Cancer* **18**(2): 225-233, McLoone, J. K., K. J. Watts, S. W. Menzies, K. Barlow-Stewart, G. J. Mann and N. A. Kasparian (2013). "Melanoma survivors at high risk of developing new primary disease: a qualitative examination of the factors that contribute to patient satisfaction with clinical care." *Psychooncology* **22**(9): 1994-2000.

<sup>13</sup> Nodal relapse refers to a metastasis of melanoma to the lymph glands closest to the original site, but not to anywhere else in the body.

changing nature of participants' needs for information and support as they moved through diagnosis, surgery, the immediate post-surgical period and on to the long-term effects of surgery.

### Summary of each study

Each of the ten studies identified as meeting the criteria was thematically summarised in the tables below. As noted in a systematic review undertaken by the National Institute for Health and Care Excellence in the U.K. (NICE 2015), differences in research questions, methods and participant populations, especially in relation to the kind of melanoma and the stage of melanoma, are obstacles to meta-analysis; the studies in the present review are therefore summarised individually in tabular form and presented in date order of publication.

**Table 5:** Summary of study by Hajdarevic, Hörnsten et al. 2010

<i>Patients' decision-making in seeking care for suspected malignant melanoma</i> (Hajdarevic, Hörnsten et al. 2010)
<b>Location and population:</b> Sweden. 21 participants (11 women, 10 men), aged 18 to 80 years, diagnosed within two years prior to the study.
<b>Methods:</b> One semi-structured interview per participant, interviews ranged from 30 to 60 minutes. Grounded thematic content analysis.
<b>Findings:</b> Data analysis identified a model describing the process of deciding to seek medical advice. In this model, the discovery of a suspect skin lesion starts a time-consuming negotiation of balancing on the one hand deterrents deriving from the personal, social and healthcare-related sphere and on the other hand integration of an increasing threat. Eventually, the negotiation ends in a turning point and a quick decision to seek care.

**Table 6:** Summary of study by Hajdarevic, Schmitt-Egenolf et al. 2011

<i>Malignant melanoma: gender patterns in care seeking for suspect marks</i> (Hajdarevic, Schmitt-Egenolf et al. 2011)
<b>Location and population:</b> Sweden. 30 participants (15 women, 15 men), aged 18 to 80 years, diagnosed within two years prior to the study.
<b>Methods:</b> One semi-structured interview per participant, interviews ranged from 30 to 60 minutes. Grounded thematic content analysis.
<b>Findings:</b> Women more often than men examine their skin and have higher attention to bodily changes and are more likely to discover the melanoma on their own. Women have a higher perception of susceptibility to melanoma, have a higher level of knowledge about melanoma and use more sources of information about melanoma than men. Women experience a time-consuming period of emotional consideration in order to commit to seeking medical advice because of not wanting to waste a doctor's time and because of the potential consequences for family and work if the diagnosis is serious. Men make fast decisions about seeking medical care, or delay because of current work-related issues.

**Table 7:** Summary of study by McLoone, Watts et al. 2012

<i>When the risks are high: psychological adjustment among melanoma survivors at high risk of developing new primary disease (McLoone, Watts et al. 2012)</i>
<b>Location and population:</b> Australia. 20 participants (11 women, 9 men), aged 34 to 74 years (mean age 57.6 years), at high risk of recurrence of melanoma, not actively receiving treatment.
<b>Methods:</b> One semi-structured interview per participant, face to face, interviews ranged from 23 to 63 minutes. Grounded thematic content analysis.
<b>Findings:</b> Fear and uncertainty are correlated to beliefs that current treatments for advanced melanoma and metastases are ineffective. Belief in early intervention and faith in clinical skin examinations facilitated healthy emotional adjustment. Participants appeared to adjust to scarring as a collateral consequence of survival. Participants would value consultations with a psychologist trained in the specific needs of people with melanoma.

**Table 8:** Summary of study by Topping, Nkosana-Nyawata et al. 2013

<i>'I am not someone who gets skin cancer': risk, time and malignant melanoma (Topping, Nkosana-Nyawata et al. 2013)</i>
<b>Location and population:</b> U.K. 45 participants (21 women, 24 men), aged 21 to 85 years, with malignant melanomas 0.76 mm or thicker.
<b>Methods:</b> One semi-structured interview per participant, face to face, interviews lasted approximately one hour. Grounded thematic content analysis.
<b>Findings:</b> Participants with thin melanomas experienced time-lapses between initial self-identification of a potential problem and diagnosis in the range of 0 to 1.5 months. Participants with more advanced melanomas reported a time-lapse in the range of 2 to 25 months. Participants responded rapidly to symptoms because of encouragement by a friend or family member, or because of their concern about changes in moles and lesions. Participants responded more slowly to symptoms because of: personal health identity as someone who is not likely to get cancer in general and skin cancer in particular; normalisation of changing moles and lesions; and a perception that other life events were more pressing. Some participants visiting a doctor for another health condition 'smuggled in' their concerns about a mole or lesion; some felt that their lack of emphasis on the symptom may have attributed to their doctor not proceeding with further investigation. Other participants said their doctors had actively countered their concerns about symptoms, telling them there was no risk or no urgency to act.

**Table 9:** Summary of study by Morton, Rychetnik et al. 2013

<i>Patients' perspectives of long-term follow-up for localised cutaneous melanoma (Morton, Rychetnik et al. 2013)</i>
<b>Location and population:</b> Australia. 29 participants (12 women, 17 men), aged 20 to 83 years (median age 62), undergoing long-term follow-up after surgical treatment of stage I/II melanoma.
<b>Methods:</b> One semi-structured interview per participant, face to face or by telephone, interviews ranged from 12 to 72 minutes. Grounded thematic content analysis.
<b>Findings:</b> Perceived benefits of follow-up care included reassurance, early detection of new melanomas and non-melanoma skin cancers, education about skin self-examination, the opportunity to ask questions and reinforcement of 'unsafe' behaviours. Concerns about follow-up care included inconvenience of travel to attend visits and lost work time. Most participants felt their follow-up intervals could be extended to 12 months if recommended by their clinician. Participants would value access to specialists for unscheduled visits.

**Table 10:** Summary of study by Walter, Birt et al. 2014

*'This isn't what mine looked like': a qualitative study of symptom appraisal and help seeking in people recently diagnosed with melanoma* (Walter, Birt et al. 2014)

**Location and population:** U.K. 63 participants (31 women, 32 men), aged 29 to 93 years, within 10 weeks of melanoma diagnosis, with thinner (<1 mm) and thicker (>2 mm) melanomas.

**Methods:** One semi-structured interview per participant, face to face, interviews ranged from 40 to 65 minutes. Grounded thematic content analysis.

**Findings:** Subtly different patterns of symptoms were experienced by those with thicker and thinner melanomas. Help-seeking was often postponed because of other life concerns. Most decisions to seek help were triggered by common factors such as advice from family and friends. There was a mismatch between the information available and the skin changes noticed by participants. Some participants did not have their developing melanomas recognised during their first primary care consultation, and were not provided with enough information about ongoing assessment and follow-up.

**Table 11:** Summary of study by Stamataki, Brunton et al. 2015

*'Assessing the impact of diagnosis and the related supportive care needs in patients with cutaneous melanoma'* (Stamataki, Brunton et al. 2015)

**Location and population:** U.K. 15 participants (8 women, 7 men), aged 27 to 78 years (mean age 52 years), diagnosed with melanoma at least 3 months and no more than 5 years prior to the study.

**Methods:** One semi-structured interview per participant, face to face, interviews ranged from 40 to 75 minutes. Grounded thematic content analysis.

**Findings:** Lack of proven adjuvant treatment caused feelings of helplessness and uncertainty about the future. Some participants felt they had not been prepared for the extent of scarring from surgery and there was discrepancy between physicians' views of a well-healing scar and participants' expectations of how a scar would heal. Surgery led to an altered body image and functional impacts on daily life resulting from lymphoedema, tiredness and pain. Participants affected by fatigue rationalised it as a normal outcome of treatment and did not seek healthcare support. As an overall impact, participants lacked reassurance about the effects of surgery. Participants felt that information was not provided in layman's terms, that it was 'front-loaded' and not given in a timely way appropriate to the phase of the patient journey, and that there were not enough opportunities to engage healthcare providers in discussion and explanation about the disease, prognosis, treatments and outcomes.

**Table 12:** Summary of study by Hope-Stone, Brown et al 2015

*How do patients with uveal melanoma experience and manage uncertainty? A qualitative study* (Hope-Stone, Brown et al. 2015)

**Location and population:** U.K. 25 participants (10 women, 15 men), aged 36 to 89 (median age 61 years), healthy survivors of uveal melanoma, 6 to 60 months after treatment (approximately 8 to 62 months after receiving prognostic information).

**Methods:** One semi-structured interview per participant, face to face or by telephone, interviews ranged from 9 to 42 minutes. Grounded thematic content analysis.

**Findings:** Prognostic information did not relieve uncertainty about the future. Different prognoses engendered different experiences of uncertainty. Seeking information did not always resolve uncertainty and could engender it. Patients managed their uncertainties by suppressing thoughts about them and by trusting in the care of clinicians and the healthcare system.

**Table 13:** Summary of study by Bird, Coleman et al. 2015

<i>Coping with melanoma-related worry: a qualitative study of the experiences and support needs of patients with malignant melanoma</i> (Bird, Coleman et al. 2015)	
<b>Location and population:</b> 11 participants (6 women, 5 men), aged 31 to 83 years, attending clinics for regular surveillance.	
<b>Methods:</b> One semi-structured interview per participant, face to face. Grounded thematic content analysis.	
<b>Findings:</b> Participants expressed a need to have their fears and worries acknowledged by others including nurses, healthcare professionals and family members. Emotional support was described as having people to talk to and involved healthcare providers. When family and friends were not available healthcare providers were chosen as a key source of support. Participants framed treatment, attending follow-up visits and compliance with follow-up visits as doing something to help themselves.	

**Table 14:** Summary of study by Stothers and McCaughan 2015

<i>Patients' experiences of coping with nodal relapse of melanoma</i> (Stothers and McCaughan 2015)	
<b>Location and population:</b> 6 participants (4 women, 2 men), aged 31 to 60 years (median age 45 years), had received a block dissection of neck, axilla or groin for nodal relapse of melanoma within the last two years.	
<b>Methods:</b> One semi-structured interview per participant, face to face. Grounded thematic content analysis.	
<b>Findings:</b> Symptom identification varied from self-identification of a lump to symptom identification by a physician during a clinical examination. Participants reported less shock on diagnosis compared to the first diagnosis and better coping skills to manage this diagnosis. Participants wanted more information about ongoing effects of surgery and about arrangements for follow-up care. Participants were not prepared for the magnitude of the effects of surgery and continued to struggle emotionally and psychologically after the physical effects had been resolved. There was a preference for a more holistic approach to follow-up care involving psychological services and a preference for synthesis in the oncological and surgical points of view related to follow-up care: participants' expectations of outcomes were conflicted by differences between positive surgical messages relating to wound healing and negative oncological projections about their cancer trajectories.	

### **Taxonomy of domains: a meta-narrative view of findings**

In an iterative process, the studies selected for the review were read and coded for themes multiple times, and key themes were drawn into a taxonomy of domains. The domains related to key phases in the progression of study participants through the biomedical trajectory of melanoma patient care. Three fundamental progressive phases of patients' experiences were identified, and one global category of experiences that occurred throughout all phases. The key progressive phases were: i) symptom identification through to diagnosis; ii) diagnosis through to treatment; iii) post-treatment. The findings within these progressive phases constituted a meta-narrative view of the melanoma patient journey, representing the study authors' interpretations of melanoma patients' descriptions of care experiences from symptom identification through to follow-up care and recurrence. Table 15 features the collective findings

interpreted as a meta-narrative of progressive patient journey.

**Table 15:** A meta-narrative view of findings from qualitative studies of melanoma patients

<b>Symptom identification to diagnosis</b>	Time lapses between symptom identification and help-seeking of 0 to 1.5 months in earlier stages of the disease and 2 to 25 months in later stages. Patterns of symptoms different between early and late stages of disease.
	Help-seeking after symptom identification can be a time-consuming process of personal negotiation and persuasion by others eventually leading to a turning point in which there is a perception of the symptom as urgent and a quick decision is made. Help-seeking may be postponed because of: concerns about wasting physicians' time; concern that a diagnosis will lead to a disruption of normal life; rationalisation of symptoms against pictures of melanoma in informational material; self-beliefs about health and cancer; and normalisation of symptoms over time. Help-seeking may be facilitated by: comments by family and friends about symptoms; previous history of melanoma or knowledge of others' experiences; fear about melanoma. Delays in diagnosis can be caused by lack of recognition of symptoms by physicians and poor communication about when and how to follow up on a suspicious symptom. Help-seeking may be influenced by gender. Women may be more likely than men to identify a symptom themselves and may find the decision to seek help more time-consuming than men.
	Clear prognostic information may not relieve uncertainty about the future. Seeking information about prognosis, disease progression and treatment may not resolve uncertainty and might engender it. People may manage their uncertainties by suppressing thoughts about them and by trusting in the care of clinicians and the healthcare system.
<b>Diagnosis through to treatment &amp; recovery</b>	People who have surgery for melanoma may not be prepared for the extent of the scarring and the amount of tissue that is excised. Melanoma patients may not be prepared for the amount of recovery time required after surgery and issues that arise in recovery. There may be a mismatch between the perceptions of melanoma patients in relation to how their scars are healing and the criteria surgeons use to determine healing: melanoma patients may expect better aesthetic outcomes and less impact on physical functionality.
	People who have surgery for melanoma may deal with: appearance-related concerns and altered body image; immediate functional impacts of swelling, scars, lymphoedema and fatigue; and issues related to satisfaction with the experience of surgery.
	It may be difficult for melanoma patients to synthesise the different perspectives of oncologists and surgeons with respect to the outcomes of treatment and the impact on prognosis.
<b>Post-treatment</b>	Melanoma patients may be uncertain as to the schedule for follow-up oncological reviews, and may prefer to be given a schedule of regular reviews, and especially clinical skin examinations, to assuage fears about recurrence. Ease of access to their specialists outside of scheduled review appointments may be important to people with melanoma. There may be uncertainty about what to expect in follow-up reviews; reviews may be perceived as inadequate to personal needs if attention is not paid to holistic personal issues as well as biomedical status. There may be issues for melanoma patients in taking time off work to attend follow-up reviews and travelling to the location for follow-up reviews.
	People with non-specific symptoms and ongoing fatigue following treatment—including surgeries, chemotherapies and radiotherapies—may feel they are not believed and may struggle to find adequate information and support for their situations.
	People diagnosed with and treated for melanoma may not identify themselves as having cancer, and may not feel they have a legitimate claim to seek support for ongoing emotional and psychosocial issues.
<b>Outset-to-outcome</b>	People with melanoma may experience issues with the provision of information; they may find that information is 'front-loaded' in contrast to being supplied throughout the patient journey. Melanoma patients may not be provided with timely information about the disease, treatment options, impacts of treatment, outcome scenarios, how to identify recurrence, schedules for follow-

	<p>up reviews and what to expect in follow-up reviews, and how to make relevant changes to lifestyle to prevent recurrence.</p> <p>People with melanoma may find that the information that is provided uses medical terminology that is difficult to comprehend and is not explained in 'layman' terms.</p>
	<p>Melanoma patients may perceive a lack of opportunities to spend time with healthcare providers in order to resolve queries and explore concerns.</p> <p>It is unlikely that people with melanoma will have their emotional and psychosocial issues addressed by the healthcare providers who are attending to the management of their disease. It is unlikely they will be referred to psychological or counselling services, though they may be referred to support groups of fellow melanoma patients.</p>

## 2.4 Literature review discussion and conclusion

The findings of this review suggest there is as yet only a small amount of qualitative research on melanoma patients' perceptions of healthcare. Bird, Coleman et al. also found that "little evidence exists about the nature of patients' support needs or their experience of having melanoma" (Bird, Coleman et al. 2015:937) and Stamataki, Brunton et al. noted that "qualitative studies on the experiences of patients diagnosed with melanoma are scarce" (Stamataki, Brunton et al. 2015:780).

Despite the small yield of qualitative studies reflecting patients' perceptions of melanoma healthcare, there was a consistent 'throughline' in the meta-narrative, which was the crossover between experiences directly related to the progressive events and circumstances of medical services and healthcare delivery, and experiences related to the psychosocial impact of having the disease. This intertextuality has pragmatic consequences for the translation of research findings into healthcare policy and practice. It points to a need for the provision of professional psychosocial support services adjunct to the medical management of melanoma. Some of the studies 'teased out' the areas of psychosocial impact that had implications for policy-making and the practice of melanoma healthcare. Stamataki et al. (Stamataki, Brunton et al. 2015) differentiated between: emotional effects due to uncertainty for the future, body image and fear of the sun; functional effects due to ongoing symptoms; effects on personal relationships; and health system and information needs. McLoone et al. (McLoone, Watts et al. 2013) identified that melanoma patients struggle to identify themselves as cancer patients and as a result do not perceive entitlement to seek psychosocial support. That study also identified links between psychosocial adjustment to melanoma and a reliance on regular clinical reviews to ensure early intervention in recurrence. The collective findings of these studies suggest that providing formalised emotional and psychosocial support would be a way of managing the burden of the disease on people, and would also be a way of managing the burden of the disease on healthcare systems, since anxieties drive people with melanoma to rely heavily on follow-up care. These examples contextualise

the ways in which qualitative research on melanoma patients' emotional and psychosocial experiences relates to the provision of care; they also promote a rationale for investigating melanoma patient experience as a discrete area of interest within the wider sphere of cancer patient experience.

### **Emplotment of patients' experiences as a meta-narrative**

In the taxonomy of research domains, the findings of each of the studies were thematically organised according to progressive phases in the biomedical trajectory of melanoma diagnosis and management. This taxonomy formed a meta-narrative view of the melanoma patient journey. In some studies the focal period of the patient journey was made explicit, such as the period from symptom identification to first point of medical contact specified in the article, *'I am not someone who gets skin cancer': risk, time and malignant melanoma* (Topping, Nkosana-Nyawata et al. 2013), or the period of follow-up care specified in the article, *Patients' perspectives of long-term follow-up for localised cutaneous melanoma* (Morton, Rychetnik et al. 2013). In studies that looked at patient experiences across the trajectory of care, the focal period was implied rather than made explicit by the study authors. This was evident, for example, in the article, *Patients' experiences of coping with nodal relapse of melanoma* (Stothers and McCaughan 2015), which, when analysed, covered the period from symptom identification to follow-up care. The titles of the articles were not always clues to the period of patient journey that was of interest: in the article, *Assessing the impact of diagnosis and the related supportive care needs in patients with cutaneous melanoma* (Stamataki, Brunton et al. 2015), the title points to the period of diagnosis however the study relates to care experiences throughout the patient journey.

Some papers engaged in within-study emplotment of patients' experiences by identifying the changing nature of patients' care experiences over time and accounting for transitions between experiences. This kind of emplotment was deliberate in the article, *'This isn't what mine looked like': a qualitative study of symptom appraisal and help seeking in people recently diagnosed with melanoma* (Walter, Birt et al. 2014) which modelled pathways to treatment by tracking the events and processes described by patients in calendars and diaries. Emplotment of patients' healthcare experiences was also deliberate in the article, *Patients' decision-making in seeking care for suspected malignant melanoma* (Hajdarevic, Hörnsten et al. 2010), which identified a model of transitional decision-making that occurs in the period between symptom identification and first clinical presentation, and which involves a period of resistance to medical



care.<sup>14</sup>

The changing nature of patients' care experiences over time and transitions between experiences were not, however, emplotted in most studies. The article, *How do patients with uveal melanoma experience and manage uncertainty*, for example, identifies participants' descriptions of uncertainty as occurring across different periods of time from the point of prognosis but is not concerned with mapping the transitions from one kind of uncertainty to another. Commonly, patients' experiences were thematically organised across the period of time of interest to the study. The article, *Coping with melanoma-related worry: a qualitative study of the experiences and support needs of patients with malignant melanoma* (Bird, Coleman et al. 2015), for example, thematically identifies issues that occur across the journey—such as concern about being believed and anxiety about recurrence—but does not engage with how those themes develop and change over time.

## Conclusion

To my knowledge, this is the only review of primary qualitative studies that have investigated melanoma patients' perspectives on their healthcare experiences. Overall, the review points to the early development of an archive of qualitative findings that may be built on in the present study. Though existing qualitative studies of melanoma patients' perceptions of care do not display explicit engagement with the whole plot of the patient journey,<sup>15</sup> the review established a taxonomy of research domains that synthesised findings into a meta-narrative framework reflecting the melanoma patient journey from symptom identification to outcome and follow-up care. Through this 'lens', the review distinguished investigative interest across phases of the patient journey.

The studies identified in this review all used single narrative interview as the method of data collection; none used multiple interviews or ethnographic methods in which

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<sup>14</sup> This model echoes an early phase in the quest narrative, which can be identified as a 'refusal to the call', referring to the period of time in which the central character baulks at taking action in response to a challenge to her or his normal way of life. A correlation between this archetypal narrative and the melanoma patient journey is investigated further in Chapters 5, 7 and 8.

<sup>15</sup> The study by Tan, Butow et al. 2014 investigated psychosocial impact and coping in relation to high-risk melanoma patients and their carers throughout the course of the disease. They emplot their findings in a meta-narrative of patient journey in a 'three-act' plot of diagnosis, treatment and survivorship. Within each segment they list the types of issues that characterise the segment and bring a personal perspective to the issues with a quote from a participant. The quote acts to personalise the presentation of themes. The authors present also a category of global themes comprising issues that have occurred throughout the melanoma journey. This was the only empirical study identified in the review that constituted a meta-narrative view of the melanoma patient journey. That it did so from the perspective of carers as well as patients excluded it from review in this study, which prioritises patient perspective, however it offers an interesting example of how meta-narratives of patient journeys can reflect the healthcare experiences of melanoma patients.

researchers become immersed in the culture of the population under study (Goodson and Vassar 2011). Nor did the studies identified in the review look to alternative sources of qualitative data beyond interviews, such as autobiographical stories written by people with melanoma about their care experiences. The review established that a cross-disciplinary, medical humanities approach, using narratological or literary forms of data analysis for example, has not been utilised in qualitative studies of melanoma patients' perceptions of care.

The content and methodological gaps in the literature identified in the review indicate opportunities for the present study to advance the qualitative investigation of melanoma patients' perceptions of care experiences. These opportunities include:

- gathering qualitative data on melanoma patient journey
- collecting data by modes of inquiry other than single narrative interview
- undertaking cross-disciplinary modes of content analysis in addition to conventional grounded thematic content analysis
- explicitly contextualising research findings in relation to the patient journey.

In the conclusion to the thesis in Chapter 9, I synthesise the findings of existing studies as identified in this review with the findings of the present study in order to present an 'updated' archive of melanoma patients' perceptions of healthcare experiences.

## **2.5 Narrative modes—foundation concepts**

In this section I explore and identify the theories that inform discussions about narrative modes of research and narrative conceptions of patient experience in order to establish a scholarly context for the study. The format for this review is descriptive, and non-systematic in that it establishes no “explicit and auditable protocol” (Sandelowski 2008). In order to ensure that the theoretical constructs under review are well defined and well researched, the literature selected for discussion is sourced from peer-reviewed journals distributed by the databases tabled in the introduction to this chapter.

### **Foundations of narrative as ontology**

The key assumption under investigation is narrative as an intrinsic mode of comprehending experience: “That life has to do with narration has always been known and said” (Ricoeur 1986:1) On the shoulders of the generations of literary and narrative theorists since Aristotle who have tried to understand exactly what life has to do with narration, narrative inquirers and narratologists seem to have arrived at a largely unified position: humans are inherently narrative (Polkinghorne 1991, Parry 1997, Greenhalgh and Hurwitz 1999, Bruner 2004, MacIntyre 2007, Charon 2012, Hardy 2014). “We dream in narrative, day-dream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticize, gossip, learn, hate and love by narrative,” wrote Hardy (Hardy 1968) some forty years before the arrival of social media. Now, with autobiographical renderings of personal narrative swelling the content of You Tube and Facebook daily, it seems obvious that we are “incapable of not narrating our experiences both to ourselves and each other” (Parry 1997:6). The underlying paradigm is that narrative is the “cognitive organizing process” (Polkinghorne 1991:136) by which humans comprehend the complex and intersecting multitude of features that comprise experience—that “stories provide a means of making sense of one’s life and experiences, and coherent stories are connected to coherence of life and understanding” (Thomas-MacLean 2004:1648).

There is contention about the degree to which narrative as a phenomenon should be promoted as a means of identifying and representing experience. Woods asserts the limits of narrative as a dominant qualitative research approach in the field of medicine and healthcare and suggests that we should “explore non-narrative ways of understanding and articulating the experience of illness and its impact on the self” (Woods 2011:76). She refers her readers to Strawson who perceives the modern paradigms of the narrated identity to be hyperbole. Strawson’s treatise, ‘Against Narrativity’ (Strawson 2004) rails against what he sees as the widespread fashionability

of the dominant paradigm of the “narrativity camp” (Strawson 2004:437) and the assumption that all humans locate experience in time in the same way. Further, there is an apprehension that with uncritical approaches to the place of narrative in human experience, there will be an inappropriate ‘tidying up’ of experience. Mink notes that although narrative is a primary mode of communication, “Stories are not lived but told. Life has no beginnings, middles, or ends” (Mink 2001). In reality, then, the “complex, spatial embeddedness” (Mattingly and Garro 2000:37) of life and its “continuous groping for meaning” (Wikan 2000:234) point to the impossibility of authentically capturing all that experience in a story.

Despite this debate, universal acceptance can be seen for the idea that narrative is at least one of the inherent cognitive mechanisms humans have for managing and representing experience and that it can be an apt means of investigating experience. Ricoeur (Ricoeur 1984) makes the case that narrative is privileged over other forms of expression by its particular relationship with temporality: through narrative we can express experience as it occurs in a particular period of time—past, present and future. Bruner takes up this idea with his notion that we “seem to have no other way of describing ‘lived time’ save in the form of a narrative” (Bruner 1988/2004:692). He takes this idea further, suggesting that in the end, not only does narrative imitate life by representing the movement of time but we come to identify time in our life by our narrative expression of it: “...eventually the culturally shaped cognitive and linguistic processes that guide the self-telling of life narratives achieve the power to structure perceptual experience, to organize memory, to segment and purpose-build the very ‘events’ of a life” (Bruner 1988/2004:694). These reflexive negotiations between life, narrative and the nature of experience ideologically and also functionally shape the way we approach the use of narrative in social science research.

## **2.6 Narrative and social science research**

The focus on narrative modes of comprehending and representing experience that began in the 1960s established a paradigm in which story adequately “accounts for human experience” (Coreil 2009:69), resulting in the ‘rise and rise’ of narrative inquiry in qualitative research (Sommer 2004:3). The debate about narrative in this arena is not whether narrative is an apt or overly promoted means of comprehending and representing human experience, but what kind of approach to narrative is apt and authentic.

Bruner identified a methodological differentiation between ‘paradigmatic-type narrative inquiry’, which mines narrative content for data that can be disarticulated and

categorised, for example into themes, and ‘narrative-type narrative inquiry’ that draws narrative descriptions of events together into a story plot that accounts for phenomena, for example in histories and biographies (Bruner 1986).

Clandinin and Connelly have argued that all narrative inquiry should be understood as a means of entering experience through story: “With narrative as our vantage point, we have a point of reference, a life and a ground to stand on for imagining what experience is and for imagining how it might be studied and represented in researchers’ texts” (Clandinin 2000:xxvi). Their concern is whether there is an ontological commitment to a relational engagement with the study participants and an epistemological affiliation for the authentic telling of their stories in the narrated research text. Caine, Estefan and Clandinin also differentiate between narrative inquiry as a form of research that is “a transaction between people” (Caine, Estefan et al. 2013:578) and narrative research, which is research that uses stories as data. In that conception, narrative inquiry is research framed by a narrative view of experience; it attends to “place, temporality, and sociality within our own life stories and within the experiences of participants” (Caine, Estefan et al. 2013:576). In contrast, narrative research that uses the events and happenings described in stories and narratives to draw out, represent or promote specific “problems, encounters or observations” (Caine, Estefan et al. 2013:575) is not narrative inquiry.

Polkinghorne critiqued the differentiation of narrative methodologies by Connelly and Clandinin as limiting narrative inquiry to one form of discourse—in which people tell stories—rather than allowing for straightforward discourse in which explanations or opinions are given. He did not discriminate between kinds of narrative inquiry/research but did take an interest in what he called narrative configuration, which he described as “the process by which happenings are drawn together and integrated into a temporally organized whole” (Polkinghorne 1995:5). In his idea of narrative configuration, the emplotment of events by research participants, and by researchers, represents experience in segments of time that feature “the phenomenon of individual protagonists engaged in an ordered transformation from an initial situation to a terminal situation” (Polkinghorne 1995:7). Polkinghorne considered that the unique quality of experience and the fullness of experience are represented in the telling of experience as story.

Riessman, an advocate of a wide interpretation of narrative inquiry, referred to “the broad field of narrative inquiry” (Riessman 2008:3) in which interviews are “narrative occasions” (Riessman 2008:23) from which researchers emerge with a text they will interpret. The perspective Riessman brings is that there is a “family of methods for

interpreting texts that have in common a storied form” (Riessman 2008:11), the most popular being thematic narrative analysis, which attends to what is said, and structural analysis which attends to how it is said. She identified narrative thematic analysis as being different from grounded analysis in that narrative scholars “keep a story intact by theorising from the case rather than from component themes (categories) across cases” (Riessman 2008:53).

The dichotomising of epistemological approaches to narrative research presents as a kind of spectrum of narrativity, with participants’ stories examined for data on one end of the spectrum, and stories retold by researchers in narrative form at the other end. The issue for the present study is an understanding that one approach is not better than the other but that the spectrum is taken into consideration so that the mode suits its purpose, so that the fullness of the melanoma patient experience is identified, and so that the diverse ideas about narrative modes of inquiry are exposed.

## **2.7 Narrative research and healthcare**

The idea of a spectrum of narrativity in narrative modes of research has particular relevance to patient experience research that, as noted in Chapter 1, veers between the intent to comprehend patient satisfaction with services and the intent to comprehend the nature of patients’ healthcare experiences. Ziebland and Coulter convey healthcare as a knowledge-based system that draws on not only “scientific knowledge about biological processes, epidemiological knowledge about patterns of disease and risk factors, and clinical knowledge about how to treat medical problems” but also “how people experience health, illness, treatment and the delivery of care” (Ziebland, Coulter et al. 2013:1). In their conceptualisation, narrative forms of inquiry into patient experience are framed by the pursuit of data contextualised by a particular issue or as a contribution to a specific gap in information. This gives an overarching purpose to the research and makes its contribution to healthcare policy and practice explicit. It also sits akilter with the ideas of Clandinin et al. that narrative inquiry should be a research medium unfettered by agenda other than to explore the nature of a particular experiential phenomenon. The acquisition of knowledge as a goal for narrative research thus inclines towards methods like Polkinghorne’s ‘paradigmatic-type narrative inquiry’ and Riessman’s thematic forms of analysis. Being absorbed in the stories that patients tell and moved by the experiences they recount is valued in research methodologies such as ethnography, but is not an explicit objective in qualitative patient experience research.

The problem of this is paradoxical: the methodologies that constitute ‘narrative research’ do not have to take into account the story of the participant. In the first waves

of narrative research, affiliation to story was considered integral: “Narrative analyses of text force scholars to attend first to what is placed immediately before them—stories—before transforming them into descriptions and theories of the lives they represent” (Sandelowski 1991:162). Current methodologies for narrative research, however, can legitimately display analytic inattention to the chronicle of unfolding personal drama in illness narratives, despite the narrative nature of the data and the narrative mode of inquiry by which data are collected. De Fina and Georgakopoulou frame this as the divergence between narrative as an epistemology and narrative as method (De Fina and Georgakopoulou 2011:19).

## **2.8 Narrative medicine and illness narratives**

The fields of narrative medicine and medical humanities bring cross-disciplinary perspectives to that divergence. The literary theorists and analysts, medical practitioners, sociologists and social scientists in these emerging domains account for both knowledge acquisition and affiliation for the patient storyteller in their examination of autobiographical, biographical and fictional representations of illness and patienthood. Their interest in these illness narratives, or pathographies as they are sometimes called (Hawkins 1999), is focused on the content of the stories—the experiences of the storytellers—and also on the function of narrative in representing illness and care experiences (Gale, Mitchell et al. 2003, Kalitzkus and Matthiessen 2009, Charon 2012, Coulter and Locock 2014). Goyal (Goyal 2013) notes that scholars of medical humanities and narrative medicine attend to the meaning-making choices of storytellers as they sculpt their experiences into a narrative form.

The paradigm of narrative medicine is that the practice of medicine can be understood conceptually as an interchange of stories. When patients talk about their symptoms, they are telling stories of what happened and how it felt when that happened, and when doctors write referrals and write up their notes, they are telling stories of their patients. Thus “the care of the sick unfolds in stories” (Charon 2012). Affiliation with the ill person’s narrative is “the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness” (Charon 2007). Affiliation is an ethical endeavour that seeks engagement with the events of a patient’s “clinical plot” (Mattingly 1998) as a drama that is unfolding for the ill person. The drama is represented in the ontological expressions of being ill and the phenomenological expressions of having illness experiences that are exposed in over-time descriptions of illness and healthcare events. When the narrative text is not presented whole, or when clinicians attend to only one part of a patient’s narrative, the context of time, progression and meaning-framed

change becomes lost (Frye and Lee 2006:218) and experiences of healthcare become thematic entities.<sup>16</sup> The consequence, at least, is that the nuances of incremental experiences of healthcare are left unexposed. The ontological perspective of narrative medicine is underscored by respect for the experience of the narrator. Charon says: “Whether the issue arises from the laboratory, the clinic, or the polis, we do not serve ourselves or our patients well by underestimating their complexity. To face them fully, one needs at one’s disposal a way of knowing that exceeds the technical or the theoretical, that is equipped to absorb and comprehend the situated, unruly, contradictory, meaning-saturated levels of experience” (Charon and Wyer 2008:296).

Proponents of narrative medicine look to the precepts of literary theory as a means of developing competence in comprehending a patient’s personal narrative (Sugarman and Sulmasy 2010:166). Charon explains this competence as a “combination of textual skills (identifying a story’s structure, adopting its multiple perspectives, recognizing metaphors and allusions), creative skills (imagining many interpretations, building curiosity, inventing multiple endings), and affective skills (tolerating uncertainty as a story unfolds, entering the story’s mood)” (Charon 2004:862). In this conception, character and plot are more than literary devices by which a story can be constructed and deconstructed, though they are these also: they are intrinsic to the representation of the complexity of lives told in illness. Engagement with both content and structure in spoken and written narrative texts facilitates clinicians to access what is both explicit and implicit, and both clinically relevant and subjectively significant, in the stories patients tell about their illnesses.

## **2.9 Sharing precepts: narrative inquiry, narrative medicine medical humanities**

Narrative inquiry into patient experience shares the precepts of medical humanities and narrative medicine when it “embraces narrative as both the method and the phenomena of study” (Pinnegar and Daynes 2006:5)—when it has the competence to understand the narrative acts and culturally shared narrative resources by which people convey lifeworlds of illness and patienthood.

The refinement of this competence for narrative inquirers relates firstly to the kind of illness narrative that is being investigated. Woods identifies “continuities between, for example, hospital anecdotes, published autobiographies and diagnostic interviews” (Woods 2011:74). Whereas illness narratives were first defined by their longitudinal accounts of illness in autobiographical, biographical and also fictional books, all kinds

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<sup>16</sup> As was noted in the extant studies identified in the literature review.



of texts that represent “medical, psychological, and psychiatric” events (Schioldann 2003) are now considered illness narratives. Illness narratives are, therefore, any “narrative objects” (Meuter 2011) that have been authored prior to coming to the notice of readers or researchers, or that are the product of the discourse and narration about illness that occurs, for example, in clinical and research settings.

Different modes of production—oral, written, co-created in interview—and kinds of illness narratives (Hydén 1997:49, Kalitzkus and Matthiessen 2009)<sup>17</sup> shape the kind of narrative competence that might be practised. In autobiographical pathographies found in books, blogs and diaries, for example, the content is written and unsolicited. The authors have defined the boundaries, structure and content of the story that is told. Illness narratives derived from interview transcripts and forms of ethnography are inherently biographical, constructed by researchers from the representations of experiences elicited from patients and observed by the researcher. Researchers, as biographers, define the boundaries, structure and content of the pathographies they create. While both texts incorporate ‘first-person’ accounts, the illness narrative as unsolicited autobiography directly articulates the perspectives of the person with illness, while the illness narrative as biography reflects the perspectives of the person with illness as well as those of the researcher or clinician who took part in the co-creation. Narrative competence in narrative inquiry requires an appreciation for, and capacity to distinguish between the skills required for, a wide range of narrative texts.

The refinement of narrative competence in narrative inquiry relates also to knowledge of the ways in which illness narrative texts are at once unique and also universal. Conrad and Barker suggest the relevance here of a cross-disciplinary schema that navigates the social construction of illness through narrative (Conrad and Barker 2010). Greenhalgh and Hurwitz, Hawkins, Charon and Frank (Greenhalgh and Hurwitz 1999, Hawkins 1999, Charon 2007, Frank 2013) have articulated the idea that the expression of the experience of illness is a complex undertaking that people manage with the use of culturally-shared narrative tools. Employing these tools, people gather memories, images, feelings and thoughts into a narrative ‘bundle’ that uniquely and also socially conveys what happened and what mattered to them about what happened. Examining the enactment of this process in clinical and therapeutic situations, Mattingly and Garro (Mattingly and Garro 2000) note that people implicitly and explicitly use socio-culturally universal narrative processes in order to organise their stories of illness and

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<sup>17</sup> Kalitzkus and Matthiessen, for example, conceive a typology of illness narrative genres and a discussion on modes of production of illness narratives in relation to narrative-based medicine: Kalitzkus, V. and P. F. Matthiessen (2009). "Narrative-based medicine: potential, pitfalls, and practice." *The Permanente journal* 13(1): 80.

experiences of patienthood. Modelling narrative ways of thinking on the lived and imagined stories they are audience to, ill people become creators of the lived and imagined stories that other people are audience to—and so the process of socially-constructed narrative ways of thinking and representing is taught and reinforced.

As noted in Chapter 1, a culturally universal storytelling convention of the linear sequence representing progression of time and place (Grabes 2013)<sup>18</sup> comprising a beginning, middle and end (Greenhalgh and Hurwitz 1999). Within and around this structure are characters, events and outcomes, some of which are so commonly found in stories that they become archetypal of the context in which they are told. As Murray tells us, “Narratives do not, as it were, spring from the minds of individuals but are social creations. We are born into a culture which has a ready stock of narratives which we appropriate and apply in our everyday social interaction” (Murray 1999:53). The act of recounting personal events and representing personal meaning is underscored by the obligations of narrative genre and the pressures of character archetypes.

## **2.10 Quest narratives in healthcare discourse**

Identified in various forms and examined in innumerable ways by folklorists, psychologists, philosophers, anthropologists, sociologists and literary analysts, the transformation narrative—also called the hero journey and quest narrative—is the ubiquitous fundamental tale that lies at the heart of myths, legends and modern popular stories (Campbell 1949/2008, Frank 1995). In this narrative, 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. This narrative is depicted in the simplest of stories told and also the most epic. “Stories about people transforming, often agonisingly, from one shape to another are not just ancient, they’re primal. They occupied the earliest storytellers and continue to occupy us now” (Shaw 2010).

Sociologist Arthur Frank sparked a wealth of work on transformation narratives and illness with his typology of three core transformation narratives told by people experiencing disease and disability: restitution, which is the mission to return to the way

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<sup>18</sup> Richardson notes that oral storytelling may not always be sequential: it may be circular, contradictory, antinomic, differential, conflated and dual or multiple. Richardson, B. (2002). *Beyond story and discourse: narrative time in postmodern and non mimetic fiction. Narrative Dynamics: Essays on Time, Plot, Closure, and Frames*. B. Richardson, Ohio State University Press. For an overview on sequential storytelling, see Grabes, H. (2013). *Sequentiality. The Living Handbook of Narratology*. C. Meister. Hamburg, The Interdisciplinary Center for Narratology (ICN).

things were; quest, which is the belief that illness is or will be personally or spiritually transcendent; and chaos, which occurs when an ill person feels no longer in charge of his or her transformation—when obstacles arise that make the goals seem unobtainable, the return to some kind of ordinary world has become inconceivable and the imagined future that made the journey worth going through is lost. In Frank's conception, people do not necessarily stay with one narrative or another. The boundaries of the typology are fluid because they relate to identity transformation—the different narrative identities people bring to illness, construct in response to illness and shift in and out of in illness. Building on Frank's work, Smith and Sparkes (Smith and Sparkes 2008), Couser and Mairs (Couser and Mairs 1997) and others have gone on to conceptualise illness and disability as having a distinct narrative culture that is shaped by the story creation processes and normative narratives of the wider culture in which they exist.

Of the three narratives Frank identified as typical in illness, he found that the quest narrative, "in which people understand illness as a source of some insight" (Frank 2004), is most commonly featured because restitution leaves 'nothing to show' for the arduous journey that has been taken, and chaos has no narrative with which to express itself. The structures and process of story creation cannot be produced when the "conventional metaphors and imagery, and standards of what is and is not appropriate to tell" (Smith and Sparkes 2008) are no longer relevant to a person's experience. In that circumstance, a person with a disease may face a narrative crisis: how to connect with an audience with ingrained narrative norms, and in particular, how to locate a sense of self as protagonist.

Embedded in this narrative are the values and "proairetic codes" (Herman 2000:4) that people bring to their experiences of illness, making the creation of an illness narrative at once a unique and also universal act, and the representation of experience that comes of this act which is also unique and universal. The narrative models we adopt and live by interplay in our lives to inform our perspectives, desires, self-identity and expectations of the roles others play in illness.

Frank's quest version of the transformation narrative is articulated in an archetypal socio-cultural narrative that has received wide attention in the form identified by mythologist Joseph Campbell as "the hero journey" (Campbell 1949/2008:57). As Shapiro notes, it is the archetypal story "in which the reluctant hero (the patient) is summoned (by illness) to confront monsters and demons (both symptoms and medical treatment)" (Shapiro 2009:14). It encompasses the outward journey that a protagonist takes, and also the inner transformation, and entwines the two to encapsulate the

entirety of the experience. Campbell made the contribution of this particular transformation narrative on the basis of his research in comparative mythology. He was informed by the philosophies on the human psyche and mythology of psychiatrist Carl Jung (1875–1961) whose work Campbell edited. He was also influenced by the work of ethnographic anthropologist Arnold van Gennep (1873–1957) who had identified three broad universal stages to the rituals that define personal and social liminalities in his 1909 book, 'Rites of Passage'.

Our cultural association with the archetypal central character of this quest narrative as an identity in patienthood, and our resonance with the concept of an entwined inner and outer journey, is apparent in the language we use, which becomes metaphoric of war: people 'battle', 'fight' and 'survive' illness. Forging alliances with medical practitioners is 'beating' the disease and 'doing what it takes'. Trials and obstacles are 'won'. We attribute the status of hero to people who endure, and applaud them with descriptions like 'she never complains', and 'he's a trooper'. In this 'triumph over adversity' (Couser and Mairs 1997:7, Conway 2007) approach to illness, triumph is not necessarily, or only, realised in wellness but in advanced states of self-knowledge or the legacies of 'holding life dear' that are left with survivors. The quest narrative characterises a normative experience of illness, and is reflected in stories of illness, because it reflects states of transition, resistance, challenge, adaption and change.

Patient-centred care policies support people as protagonists of their own journeys because when patients engage with their own healthcare, personal needs and rights are met, medical outcomes are improved, and costs are contained (Coulter & Ellins, 2007). Consequently the prime goal of the patient-centric paradigm in healthcare is to shift the burden of care from healthcare services to the patient. It can be conceived that the paradigm of patient-centred care ties into the positive transformation journey. Its global objective is to craft an identity of patienthood that consistently, reliably (Bowling, Rowe et al. 2012, Chassin and Loeb 2013) supports a person as protagonist of their journey.

### **Quest narratives as normative narratives**

Campbell established a typology of universal narrative elements that are employed in hero journey mythology to represent a transformation from ordinary person living an ordinary life to hero engaged in a mortal ordeal. He mapped out detailed plotlines and turning points, archetypal characters, universal relationships and interactions and influences that impact on the protagonist. His typology became a schema for those in the social sciences and humanities, as well as lay people seeking comprehension of the ways in which human experience accommodates conflict and disruption. In 1985, some

forty years later after the first publication of Campbell's seminal work, Christopher Vogler who was then a story consultant for Disney Films, re-booted the popularity of the hero journey model. Vogler wrote a seven-page memo to his friends and colleagues proposing that the powerful appeal of the era's most successful films, including *Star Wars*, *Indiana Jones* and *Mad Max*, was due to their use of the hero journey archetype. Vogler had studied Campbell's work at college, and could see the stages and stakeholders of Campbell's hero journey monomyth replicated in these large-budget, top-grossing, action films. Vogler's memo, which offered a simplified, practical guide to Joseph Campbell's work (Vogler 1985), spread through the film industry with the help of then newly invented fax machines, and Vogler's interpretation of Campbell's hero journey model began to influence story development in film production. Campbell himself cautioned against too literal an interpretation, or too strict an application, of these elements of his model: "The whole sense of the ubiquitous myth of the hero's passage is that it shall serve as a general pattern for men and women, wherever they may stand along the scale" (Campbell 1949/2008:101). However the toolkit Vogler produced in his adaptation of Campbell's archetypal characters and events was prescriptive and 'user-friendly'. It re-popularised the positive heroic transformation concept and his model is now used widely not only by filmmakers, but also by pharmaceutical companies and health insurance companies in branding and marketing campaigns.

The model established by Campbell and adapted by Vogler to suit modern purposes is explicit. It specifies a base structure in which there is: an interruption of the ordinary world and crossing the threshold into the special world; a road of trials and obstacles; and a road to new normal. It holds that there are seven key archetypal characters that appear in transformation: mentor, herald, threshold guardians, allies, shadows, shape-shifters and tricksters. Campbell's success with people interested in mythic consciousness, and then Vogler's success shaping that into a model for writing that resonates, was threefold: the prescriptive classifications make the narrative of positive transformation accessible; the archetypal characters and events that are identified have an 'accuracy of familiarity' with the literatures of our culture; and reflexively, the archetypes are metaphors for the characters and plotlines we employ in the cognition and expression of our most significant transformative experiences. Jerome Bruner articulates this idea in his treatise on life as narrative: "Indeed, one important way of characterizing a culture is by the narrative models it makes available for describing the course of a life. And the tool kit of any culture is replete not only with a stock of canonical life narratives (heroes, Marthas, tricksters, etc.), but with combinable formal

constituents from which its members can construct their own life narratives: canonical stances and circumstances as it were” (Bruner 1988/2004:694).

The typology of elements in the quest narrative, as laid out by Campbell and Vogler, has been identified as an apt narrative framework for understanding patient trajectory as narrative. Smith, for example, correlated phases of healing (physical, emotional, mental, spiritual) with the quest narrative phases in order to identify the roles played by nurses in patients’ journeys (Smith 2002). Ramsden mapped patients’ entries into healthcare as per the pathways into the quest narrative, identifying the patient as the protagonist and positioning healthcare providers in decision-making support roles (Ramsden 2010).

Thomson and Downe examined the relevance of the role of the quest narrative protagonist to women giving birth (Thomson and Downe 2013). In this literature, the narrative is conceived as not only metaphoric of patient experience and also analogous with patient experience but as offering an ideational analytic framework (Millar, Mulla et al. 2013) for understanding patient trajectories as patient-centred meta-narratives of patient experience. The quest narrative model is perceived as a model by which the patient story can be told from the patient’s point of view, using the framework of a narrative structure in which all parts of the patient’s journey are exposed.

Other literature reflects concern that the values of the quest narrative, in imagining a positive transformation of the central character in response to the challenging journey, or a redemption through suffering, offers no place for the expression of chaos and complexity wrought by illness and by being a patient. As noted, the “cultural meanings” (Conrad and Barker 2010:S69) of the quest narrative impose an expectation on patients that they will display heroic qualities. Martin notes that the risk of a correlating a hero narrative with its inherently redemptive outcome to the messy business of illness and patienthood is that it forcibly smooths the textured experience and makes “the transformation too complete” (Martin 2011:13).

## **2.11 Patient journey and clinical process mapping**

If the quest narrative is a literary metaphor for the transitions people make through illness and healthcare, the concept of patient journey is a “pragmatic metaphor” (Biswas 2010:411) for the transitions people make through illness and healthcare. The phrase ‘patient journey’ is not standardised in healthcare; instead its meaning is contextualised by its use within particular healthcare domains, and also within fields of inquiry related to the humanities. It is framed variously as: a health trajectory within a specific medical condition (Arksey and O'Malley 2005); a technologically tracked movement through departmental or institutional healthcare services (Henly 2011); a model of

pharmaceutical use; a person's psychosocial transformational experience in response to illness; and a genre of narrative describing experiences of patienthood and/or illness. In this diverse and increasingly traversed semantic terrain, numerous disciplines and sub-disciplines have planted flags, including health systems researchers, information technology designers, organisational specialists, narrative medicine practitioners, business analysts, marketing strategists and pharmaceutical marketers.

A patient journey map is a representation of the journey, the form of which is determined by the agenda of the 'patient journey storyteller'. In healthcare system discourse, a patient journey map may comprise clinical pathways in hospital settings, while in medical discourse a patient journey map may represent the phases of a disease. Patient journey maps also feature in pharmaceutical marketing discourse characterising the decision-making pathways of people who use medication, and in healthcare insurance discourse, in which they characterise time frames of events that move a person from pay-out for illness or injury through to the time payment can finish.

Conceptualisations of trajectory in healthcare have foundations in the Corbin-Strauss-Model proposed 25 years ago to comprehend the nature and stages of ill health over time in chronic conditions (Corbin and Strauss 2012) and to reflect the actions taken by patients and other stakeholders (Juhnke and Muhlbacher 2013). Modern patient journey mapping, also called clinical process mapping, plots the points through which a patient transitions and also gathers data on patients' experiences of those plot points. The aim of gathering this data is improvement in efficiencies of time management and process flow. The concept acknowledges that patients are the only ones who 'see' all parts of their journey. Patients' perspectives are sought as a function of patient-centred care, which seeks to accommodate patients' needs in support of an outcome of patient autonomy from the healthcare system. Patient journey mapping that involves patient's perspectives is thus a means of qualitatively identifying systemic successes and failures in supplying quality care to patients.

Though patient journey texts commonly comprise some element of personal patient experience, they are not representative of only the patient's experience. Patient journey mapping also comprehends staff experiences at each of the plot points through which patients transition. Data are gathered from a quantitative perspective—the total number of steps taken, the total number of people involved, the total time taken to perform each process-step—as well as the qualitative perspective that comprehends the experiences of all stakeholders to the journey. Patient-journey mapping is then an integrative tool that brings together characters and plot to form a patient experience narrative.

## **Narrativity in patient journey mapping**

In narratological conceptions, these maps are texts that structure patient trajectories with a beginning, middle and end. The narrativity of the story they tell, however, is relative to the representation of personal experience in the text—the subjective meaning-making association between event occurrence and the experience of the event. The extent to which a patient journey or clinical process map represents the patient’s perspective, and the degree to which there is first-person input from the patient, depends on the interests and involvement of both healthcare stakeholders and patients. Different patient journey programs set different criteria for the balance of needs represented and met.

To understand a patient journey text as a narrative is to conceive of its capacity to invoke “an imaginative journey into a story world” (Mattingly and Garro 2000:11). In this sense, patient journey maps, like narrative research, can be located on a spectrum of narrativity, with one end most rich in the descriptive perspective of the patient, so that it “allows us to ‘see’ and understand the patient’s experience” (Trebbles, Hansi et al. 2010). An emphasis on patient-perspective narrative in clinical pathway audits is resulting in innovative methods such as storyboarding tools and templates that facilitate the “emotional story” to be told (McCarthy, O’raghallaigh et al. 2016). Ontologically, at this more narrative section of the spectrum, patients’ journeys through healthcare are conceived as complex adaptive phenomena that can be understood in a social constructionist framework (May, Johnson et al. 2016). The reconciliation of patient trajectory and patient experience in a strongly narrative patient journey map invokes the literary idea of what is at stake (Biswas 2010:75) for the central character at each plot point in a story—or for the patient at each turning point of the patient journey. By “acknowledging and relaying the human aspiration, achievements and expressions” (Morris 2013:20), such texts bring a humanities framework to the informatics tools that inform institutional and disease-based event and process-mapping and moreover, they understand “the that cohere among individuals” (Josselson 2007:5).

### **2.12 Conclusion: a cross-disciplinary way forward**

In the first section of this chapter, I reviewed the literature to establish the scope of existing qualitative investigation into melanoma patient experience and identified the archive of healthcare experiences that studies have collectively established to date. That set of experiences will be examined at the conclusion to the thesis in relation to the findings of the present study. I also examined the methods of the qualitative studies selected for review. I found that current modes of narrative inquiry in melanoma patient experience research operate within a common field defined by single narrative interview



and grounded content analysis that sets aside the temporal unfolding of personal experience in order to represent experiential themes. This findings supports the statement by Epstein and Street that, “Although a diverse endeavour, narrative research ...tends to employ specific kinds of data and methodologies which in turn generate a specific analytic vocabulary” (Epstein and Street 2011).

In the second part of this chapter, I identified that foundation concepts and practices related to narrative modes of identifying and representing patient experience display a divergence in ontological and epistemological approaches to narrativity. This divergence is framed by a focus on affiliation with patients as storytellers among medical practitioners and sociologists working with illness narratives as research texts, and a focus on experiential knowledge acquisition amongst social science scholars using narrative modes of inquiry and analysis to investigate patient experience. The divergence is not absolute but exposes a disconnection between scholars working in narratology, and social scientists working in narrative inquiry. Thus, while the “heuristic, cognitive and descriptive uses of narrative theory are by now widely acknowledged” (Sommer 2004:3), “Unhappily, the narrative field is parcelled up among several disciplines, which tend to work in casual or even studied disregard for one another’s very subject matter as well as methods and findings” (Sternberg 2003:297).

Paradoxically, in the shared interests of the two groups, there lies a wealth of opportunities to innovate in this arena. The flourishing fields of narrative medicine and medical humanities are inspiring new sources of data on patient experience, and new tools of analysis. The ontological platform of narrative medicine that “illness unfolds in stories” is being interplayed with a healthcare paradigm of patient-centric care to produce wide-ranging interest in patient stories in contexts such as auditing of clinical pathways. Patient stories that are pathographies—that tell of the unfolding psychosocial impact of illness and medical care<sup>19</sup> alongside the chronological trajectory of events—are now conceived as offering researchers rich sources of potentially surprising knowledge about being a consumer of healthcare services and about the personal relevance and safety of medical services and practices.

The opportunities for innovative cross-disciplinary approaches to narrative modes of inquiry and data analysis identified in the foundation concepts examined in this chapter can be drawn into a shared grammar (Hänninen 2004:70) or set of shared principles. These shared principles meld the intent of evidence acquisition in patient experience

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<sup>19</sup> As contrasted with representations of personal experiences sourced from research questionnaires and structured interviews.

research with affiliation for the ill person as a unique and also culturally-located storyteller, and align the precepts of literary analysis and narrative competence laid out in the medical humanities and narrative medicine with thematic analytic methodologies in social science. That set of shared principles includes:

**Understanding data as narrative texts:** conceiving of narrative inquiry in patient experience research as a mode of investigation into narrative texts that have in common a storied form.

**Exploring a range of narrative texts:** considering the kinds of narrative texts that might be relevant for gathering qualitative information and knowledge about patient experience.

**Displaying narrative competence:** bringing narratological skills in comprehending what is said and also how it is said in narrative texts of patient experience.

**Exploring a range of analytic options:** considering choices such as analysing for thematic commonalities in components of the content and analysing for commonalities in whole stories.

**Finding narrative patterns:** identifying and interpreting patterns in the narrative texts to comprehend meta-narratives of patient experience.

**Abstracting patient journey:** conceptualising patient journey as a mode of narrative inquiry that reconciles patient trajectory and patient experience in a perspective-framed meta-narrative text.

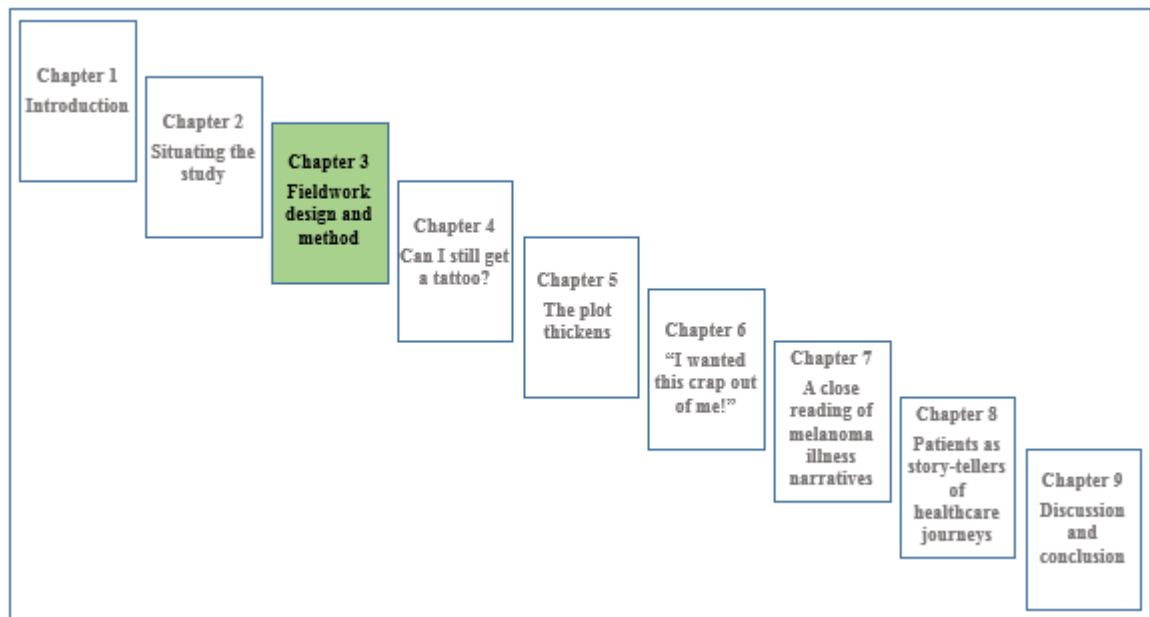
As identified in Chapter 1, the growing burden of melanoma on people and on healthcare systems calls for qualitative investigation of melanoma patient experience. As established in the review of the literature in this chapter, though qualitative investigation into melanoma patient experience is under-attended, by synthesising the findings of the narrative research done in the past ten years, a coherent meta-narrative of melanoma patient journey becomes visible. The present study builds on that knowledge base by engaging with the set of principles derived from the review of foundation concepts.

The study was thus informed by a framework that sought to: understand narrative data as narrative texts, to explore a range of texts including texts produced in interview and ethnographic research and also texts in written illness narratives, and to display narrative competence in investigating not only the experiential content of healthcare stories told by people with melanoma, but the construction of these stories to create a cohesive, culturally acceptable portrayal of what may have been, or still may be, a complex, disorderly and fragmenting set of experiences. Further, the study engaged with the cross-disciplinary precepts of exploring both thematic and whole story

analysis, identifying narrative patterns across a collective of narrative texts, and conceptualising patient journey as patient trajectory emplotted as a narrative text.

The complex interaction of chronology, setting, stakeholder interaction, and physical and psychosocial transition and transformation evident in the findings of the reviewed studies informed the rationale of the present study: to advance the detailed, textured, meta-narrative understanding of melanoma patients' healthcare experiences.

### 3 Fieldwork design and method



In the qualitative study of how people experience healthcare, there can be multiple dimensions of narrative process. The research text that comes from narrative interviews is data and it is also story. It reflects the experiences of patients in such a way as to tell something of the person as well as something that happened to the person. The representation of that complexity in research findings guides what we know of the phenomena of patient experience. This is the joy and responsibility of methodology.

#### 3.1 Phenomenology

The research question for data collection was concerned foremost with the significance of the patient journey for people diagnosed with malignant melanoma. The “abiding concern” (Van Manen 1990:31) of the project, conceptually, was to source rich experiential knowledge of patient journey phenomena in the context of melanoma, and to expose unheralded meanings of the lived experience of the melanoma patient journey.

The process of data collection therefore sought content (Freeman, Marrais et al. 2007:27) that was phenomenological (Englander 2012) rather than ‘factual’; phenomenology as a paradigmatic framework for this study sensitised the research to the seeking of data “grounded in the meaning structure of those studied” (Aspers, 2004:2). The conception of a ‘hermeneutic circle’—which comprehends the ways in which research participants and researchers work together, bringing historical and cultural backgrounds to the co-construction of meaning in every event (Laverty 2003:21)—added ontologically relativist features to the conceptual framework. The

understanding that the researcher participates in the creation of the data through interpretation of content and interaction with participants, and that together the participant and researcher make meaning, and subjectively construct the data, brought a transactional, interpretivist epistemology to the inquiry paradigm.

### **3.2 Narratology**

The research question was also concerned with understanding the relevance of the archetypal socio-literary narrative of journey and transformation identified to the ‘lived’ narratives of patient journey being undertaken by the study participants. This aspect of the research question posed, potentially, a paradigmatic challenge: hypothesis testing is generally conceived as a top-down approach that may act in contradiction to a phenomenological framework. To maintain phenomenological integrity, the source data have to be ‘protected’ from the limitations that might be incurred by the imposition of a narrative model, and yet the narrative model must be examined vis-a-vis the data in order to respond to the research question. The solution I arrived at was to test the relevance of the literary narrative in the analysis phase, as a second construct of analysis.

The first construct of analysis, then, was a grounded inquiry into the data that came from my observations of participants and their stories and reflections in interview. From this inquiry I produced a thematic research text in which I identified the events and experiences that characterised each participant’s journey. In the second construct of analysis, I placed the framework of the socio-literary narrative against the grounded research text in order to understand its relevance. The methodology supporting this second construct analysis was drawn from the precepts of hermeneutic phenomenology (Van Manen 1990, Heidegger 1992) in which lived patient journey experience is conceived as a text (Creswell 2006); narratologically the second construct analysis can be understood as an examination of the intersection between literary and lived texts. I conceptualised this second construct analysis as an exploration into the boundaries of a narratological engagement with patient experience research. I sought to understand the “relational in-between spaces” (Caine, Estefan et al. 2013) of experience that may be exposed by comparing a literary model of narrative to a conventionally produced qualitative research text.

Thus the conceptual framework for empirical inquiry comprised two theoretical constructs—phenomenology and narratology. Each in its own way responded to the goals for the research in having the potential to characterise “the meaning for several

individuals of their *lived experiences* of a concept or a phenomenon” (Creswell 2006:57).<sup>20</sup>

### 3.3 Study design

The objectives of the study design were:

- to enable the investigation of melanoma patients’ personal observations of their healthcare experiences at points along their clinical trajectories
- to facilitate the collection of rich, detailed narrative data from which key features and themes of melanoma patient experience could be identified
- to thematically identify from that rich data a meta-narrative of melanoma patient journey that characterised participants’ collective clinical trajectory experiences (see Chapter 4)
- to explore a pragmatic relationship between the fields of medical humanities and social science through the mapping of melanoma patients’ experiences of care to an archetypal meta-narrative of journey and transformation.

#### Participants

Participants were drawn from populations of people aged over 18 who had been recently diagnosed with malignant melanoma, who spoke English fluently and who were contactable by telephone and/or email. The choice to focus on malignant melanoma was made after speaking with generalist medical practitioners and oncologists, because it is a disease that affects both genders and all ages.

Given the intent to conduct in-depth, longitudinal research, and the objective of acquiring a richness of data through the ethnographic process, I had projected initially that the participant population would be up to five people. It became apparent as soon as recruitment began that participants’ fragility of health was going to shape the study. Of the nine people who agreed to take part, two died before the study began. The sample size of seven was not prescribed—rather it was ‘arrived at’.

In the recruitment process, patients who were attending the Cancer Centre at Prince of Wales Public Hospital in Sydney, Australia, and who were recently diagnosed with malignant melanoma, were asked by their attending clinician whether they would consider allowing a researcher to accompany them through some or all of their future appointments and consultations, and to observe interactions with clinical and administrative staff. A hard-copy information sheet and consent form was handed to patients if they were willing to consider participation (see Appendix A). The

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<sup>20</sup> Author’s emphasis.

information sheet outlined the process, terms and conditions of participation, and provided my contact details. During the recruitment period I was present onsite, in the waiting area of the clinic, in order to be immediately available to participants who wanted further information about the study.

As a “negotiated entry” (Connelly and Clandinin 1990:3) to the research relationship, I conducted a preliminary meeting with each participant prior to the commencement of their participation in the study. At times this was a planned event in which the participant would contact me to arrange a suitable meeting place and time. Most often it was a meeting at the hospital, arranged to coincide with their appointments and consultations. The objective of the meeting was a general, informal interaction to establish comfort and trust, to discuss any concerns regarding ethical and risk issues, and to complete any outstanding administrative tasks. This was an opportunity to “review the research question” (Englander 2012:27), so that the participant understood the nature of the research.

During the ethnographic section of the research project, I was in attendance for at least one of the participants’ clinical consultations with their oncologist. In addition to applying for and receiving ethical permission to undertake the research (see Appendix B), clinician permission for my presence onsite was sought through the management authority of the hospital. In acknowledgement that the ethnographic researcher has a obligation to the stakeholders who populate the research site (Zemliansky 2008), I established a flow of face-to-face and email communication with the supervising oncologist in the lead-up to the commencement of the study, and he introduced me to the clinic staff I would be seeing regularly in my visits to the hospital.

Site and ethics approval for the Australian research site covered the range of healthcare settings within Prince of Wales Hospital that I might enter with participants as they underwent relevant diagnostic processes and therapeutic strategies. Those settings included:

- administration and reception areas
- specialist clinician’s rooms
- a diagnostic imaging clinic
- an oncology treatment centre
- a radiology department
- a hospital ward
- the general settings of car parks and cafes within the hospital precinct.

## **Data collection**

Using the mixed methodologies of ethnography and narrative inquiry, I met the phenomenological objectives of the research. The study was designed so that I could attend in ‘realtime’ to participants’ experiences as they occurred and could use my observational notes to facilitate rich, detailed participant narratives. Purposeful narrative interviews drew participants into descriptions of the experiences that occurred outside the ‘ethnographic zone’, such as the experiences of healthcare that led up to the participant’s diagnosis of malignant melanoma. While events such as diagnostic and treatment consultations provided a chronological framework for the ethnographic endeavour, as mentioned in my autoethnographic note of Chapter 1, it was the stories participants told of their experiences and the meaning participants gave to their experiences—their “enfolding of a generative past and a future potential in the present moment, and not the location of that moment in any abstract chronology” (Englander 2012:17)—that provided the data from which key features and themes of the participant’s experience were defined. The experientiality (McGregor and Murnane 2010) that I documented was thus a result of a ‘mixed bag’ of narrative modes of expression. Working with the chronicles of biomedical and clinical events given by patients and also their oncologist, and the stories of their experiences and the interactions between them, made me witness to, and participant in, that “cognitively grounded relation between human experience and human representations of experience” (Fludernik 1996).

## **Tools of research**

The tools of research were notepad and pen, and digital tape recorder. Since the research investigated the subjective experiences of people who were in sensitive situations, appropriate tools of research seemed to be those that intruded the least. The choice of research tools was based on a principle of maximising the time spent in interaction with the participants and limiting the disengagement from interaction in order to prepare and operate recording equipment. Since clinicians were also present during ethnographic observations, the tools of research had to be those that protected the anonymity and privacy of both participants and clinicians to the greatest extent. For this reason, visual recordings were not made, and visually enacted artefacts such as photographs and patient charts were not collected as data content.

## **Preparation**

A primary issue for the study was the health condition of the participants. Given the constant referencing of biological, medical and clinical terms in the interaction with



participants and clinical staff, I was obliged to learn about the disease, to understand its definition, its symptoms, the diagnostic process, the options for treatment and the likely prognoses prior to meeting with the supervising oncologist. I read information on websites published by eminent melanoma research organisations, read personal stories on websites<sup>21</sup>, and reviewed statistical data on rates of diagnosis, survival and death in context to other cancers. As a result of my focus on the study, I became attuned to topical stories about melanoma in the media and melanoma awareness campaigns, both of which served as talking points with participants and clinical staff.

### 3.4 Field methods

The research project employed a dual layer data-collection framework. In one layer of investigation, the field-based (Aspers 2004:6) scrutiny (Millen 2000:282) of ethnographic observation was used to gather phenomenological content in progressive, immediate settings. The data from real-time observation were complemented with data sourced from informal, semi-structured discussions relating to participants' experiences prior to, and at the time of, diagnosis, when the research process had not yet commenced. Through the use of these dual, complementary strategies, the research sourced rich content.

In ethnography, the researcher's theoretical orientation frames both the process of data collection, and the nature of the data collected, making the researcher "the primary instrument for data collection and analysis" (Curry, Nembhard et al. 2009). The actions of the researcher—the methods of ethnographic fieldwork—and the research orientation (Whitehead, 2004) of the researcher—the intellectual intent and theoretical assumptions—are defined in this section.

I documented the observational episodes through handwritten notes made during and after each period of observation. The intent was to comprehensively chronicle the observational period in order to capture and recall the texture of those conversations that occurred when the recorder was not on, and to document my interpretations of participants' actions and behaviours—what I understood to be their meaning-making expressions and perceptions, within personally salient boundaries (Wolfinger, 2002:90). I used a set of categories adapted from Spradley (Spradley 1980:78 in Wolfinger 2002) to inform my accounts of the observational episodes. The categories were:

- *Event*: the situations participants were attending

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<sup>21</sup> Reading these personal stories reinforced the idea already gleaned from the literature review of undertaking a study based on an analysis of personal accounts of melanoma published to the Internet.

- *Setting*: the physical places or places
- *Stakeholders*: the people involved
- *Artefacts*: the physical things that were present
- *Activities*: the set of narrative and bodily interrelated acts between stakeholders
- *Acts*: narrative and bodily actions by the participants/researcher
- *Time*: the period of an event and the position of the event in the progressive healthcare process
- *Goals*: the things people were trying to accomplish
- *Feelings*: the emotions felt and expressed
- *Meaning-making*: perceptions and expressions of an event's significance to the participant
- *Perceptual boundaries*: the perceptual precincts that defined 'inner' experiences vis-a-vis the 'outer' events.

The semi-structured observational notes were a complement to transcription which I undertook myself and also had done professionally. Following some of the more emotionally charged sessions with participants, I found transcription to be a more steadying 'force' than documenting my reflections and perceptions, though I held as a principle that note-taking as soon as possible after the sessions brought to the ethnographic process "an accuracy and sensitivity honed by detailed observation" (Pink 2013:352).

### **Research orientation**

Prior to the commencement of the study, I was keen to decipher the aspects of orientation to the work that would impact my engagement with participants (Van Manen 1990:27). I took into consideration the following aspects of the researcher–participant relationship.

#### **Taking the position of 'other'**

A primary theoretical research orientation I took into account was my occupation of a role that was overtly 'other'. The intent was to somehow "convey how things appear to those 'inside'" (Wolcott 2008:144) from the position of a non-participant. My theoretical position was that observers "can never know *better* than an actor; a stranger cannot say *more* about any culture than a native can, but observers and strangers can see *different* things than actors and natives can" (Czarniawska 2014:45). Thus, rather than aligning with either the emic (insider role) or the etic (outsider role), the ethnographic

practices of this piece of fieldwork were driven by the idea that the line between emic and etic positions blurs in the pursuit of data collection (Wolcott 2008).

### Researcher as an 'adaptive' system

A second primary research orientation framing the ethnographic methods of this project was the idea of ethnographer as an adaptive system (Agar 2004). Based on Agar's guidelines to preparing for and managing dynamic situations in ethnographic practice, I characterised my adaption process to involve:

- *Sensitivity to initial conditions.* This tenet of chaos theory, also signified by the term 'butterfly effect' (Agar 2004:19, Resnicow and Page 2008), made provision for the fact that even minor differences in the set-up of, or during the process of, ethnographic relationships, created differences in the data. Most particularly, the changing health of some participants from session to session, and also within sessions, required a high level of responsiveness to the participants' needs.
- *Taking into account the self as ethnographic agent.* The role of the ethnographic researcher is to not only observe participants within a particular setting, but also to observe the self and to record, and account for, the effect that the researcher's presence appears to be having on the behavior and narrative of the participants. The researcher must take into account that "As qualitative researchers we tend to connect ourselves to the researched individuals on both cognitive and emotional levels" (Li 2009:109). This issue was raised fervently in two sessions in which I observed participants and their families being given the news of a poor prognosis.
- *Awareness of fractals in the 'rich point' cycle.* Agar proposes that ethnographic researchers engage heavily in addressing 'rich points' in the data collection process—"moments when something doesn't make sense, ranging from a complete surprise to a departure from the expectations that the ethnographer brought with him/her" (Agar 2004:21). In exploring a 'rich point' to understand where and how it might be placed thematically, another rich point may occur that is thematically situated elsewhere, and so the cycle goes. Given that all of the participants were significantly dislocated from their ordinary lives, and were dealing with the raw stuff of life-and-death circumstances, there were many moments of illogic in recall by participants, which I used as points by which to navigate into greater detail of events and processes.

### Conclusion field methods

The ethnographic strategies of this research project incorporated a well-considered research orientation characterised by the role of the researcher as a non-participant

‘other’, and by the idea of the researcher as an adaptive instrument of research. Reflecting these precepts, I investigated subjective experiences of healthcare journeys through the observation of participants during clinical consultations and in other settings, and collected data through transcription of recorded sessions and semi-structured note-taking outside of the observational periods. As a statement of method, I used processes of narrative inquiry in support of ethnographic data collection (Curry, Nembhard et al. 2009). These processes are detailed in the next section. Table 16 summarises the ethnographic endeavor.

**Table 16:** The methods and research orientation underpinning ethnographic fieldwork

<b>Ethnographic action</b>	<b>Research orientation</b>
Per participant observation	Non-participant, ‘other’
Shadowing of participants at healthcare events	Sensitivity to initial conditions
Structured, categorised note-taking	Taking into account the self as an ethnographic agent
Non-structured narrative interaction with participants	Awareness of the ‘rich point’ cycle
Semi-structured interviews	Ensuring a ‘fit’ landscape of representation

### 3.5 Narrative inquiry

As noted previously, the relationship between experience and the expression of experience through narrative—the “mind-narrative nexus” (Polkinghorne 1991:136)—is so greatly debated that in preparing a fieldwork proposal it seems obligatory to stake a position. To that end, three primary precepts informed the narrative methods used in this project:

- that narrative is constructed through interaction and is so subjectively formed to convey the personal perspective of the narrator that “different narrators will give different accounts of the same events and one narrator’s account may differ depending on the audience or the occasion in which it is shared” (Gale, Mitchell et al. 2003)
- that phenomenological narrative inquiry cannot assume any such thing as ‘objective reality’
- that along with the “cultural, interpersonal, and linguistic influences” (Polkinghorne 1991:135) that shape the kinds of narratives we tell ourselves and others, institutions offer us narrative models to absorb—different healthcare settings within the hospital had established their own narratives of how clinical events should proceed, and patients responded by taking on different identity roles in different settings, taking on, for example, identities as victor or victim, resilient or reliant, important or inconsequential, curious or cynical, appreciative or politically activated.

These precepts draw together in the term “storied lives” (Connelly and Clandinin 1990:2), which is an apt label for the theoretical understanding of narrative that underpins the methods of narrative inquiry used in this research.

### **Semi-structured interviews**

The interview is a generic, universal instrument of qualitative research (Englander 2012:13). Two core questions made up the ‘semi structure’ of the phenomenological interview in this design, adapted from the work of Magnus Englander (Englander 2012). Englander draws heavily on the work of Amedeo Giorgi (Giorgi 2009), whose approach to narrative inquiry is based on the philosophy of Edmund Husserl, often referred to as the founding father of phenomenology (Aspers 2004:3). The questions I most often asked were:

- “Tell me about this situation?”
- “What happened then?”
- What effect do you think this situation has had/is having on you?”

The purpose of asking participants to describe situations they had experienced or were experiencing, even when I was present during the event, was to reference the event in “indexical terms” (Jovchelovitch and Bauer 2000:1), anchoring the personal experience to place, time, action, character and intent (Jovchelovitch and Bauer 2000). In any one event, the perceptions of timeframe and setting, the nature of interactions with clinicians and other healthcare system stakeholders, and the participant’s own behavioural responses could be different for me than for the participant (Englander 2012:25). For this reason, participants were invited to plot their own journeys, selecting the features of the situation that had meaning for them and facilitating them to include and exclude actions and interactions according to their own criteria.

### **Interview technique**

This project adapted the interview technique laid out by Jovchelovitch and Bauer (Jovchelovitch and Bauer 2000) whose schema supports the project’s phenomenological precepts. The technique is prescriptive in order to facilitate and preserve the subjectivity of narrative by the participants, however the authors acknowledge that any rigidity is idealised relative to the inherent ‘messiness’ of human interaction (Smith and Sparkes 2009:8). The technique is built around three phases: main narration, questioning and concluding talk. The guidelines direct the researcher to be flexible and adaptable in responding to the subtle verbal and non-verbal clues of interaction, and to be receptive to, and act on, opportunities to exploit the interview for additional, richer content.

**Table 17:** Guidelines for narrative interviewing

Phase	Rule
Main narration	Start recording No interruptions Only non-verbal encouragement to continue storytelling Wait for the 'finished' coda before asking another question
Questioning	Only 'What happened then?' No opinion and attitude questions No arguing on contradictions No why-questions
Concluding talk	Stop recording Why-questions allowed Employ memory protocol immediately after interview

### **Conclusion narrative inquiry**

As this project entailed data collection across and throughout the trajectory of the patient journey, and since it was not possible to observe the initial points of the journey when symptom recognition led to the first contact with healthcare providers, narrative inquiry was the method by which the entire journey could be identified and emplotted. Through narrative inquiry, relationships with participants, and also their families, were established, and maintained. As the medium by which much of the 'business' of the research was conducted, the prior consideration of the complexities, nuances and processes of narrative inquiry served me well.

### **3.6 Data analysis**

The researcher, as the primary instrument of data collection, is operating not only in a professional capacity as interviewer, observer and analyst, but also in an innately personal capacity as audience and narrator, consciously and unconsciously filtering content in the pursuit of experience identification, concept meaning, and pattern-making. Data analysis was thus not a discrete phase of this research project, but a continuous formal and informal iterative action, beginning with data collection and continuing through to outcomes.

As noted, there were two constructs of analysis, each of which used coding to organise the data. The first took a ground-up phenomenological approach in which attention was paid to the assembly of "lived meanings" (Van Manen 1990:183) that melanoma patients give their patient journey experiences through their choices of which aspects to identify and emphasise in their narratives. The second took a narratological approach which investigated the intersection of the lived text (Van Manen 1990:25) of patient narratives with the structural text of the patient journey model.

## First order construct of analysis

In preparation for analysis, thick and thin descriptions and memos made in the field helped to identify core concepts, themes and meaning structures in context to participants, settings and situations, and helped me to identify and account for preconceptions, self-interests and intentional framing imposed upon the data.

As the interest of the study was in patient journey as a meta-narrative, the content was organised into data sets comprising the healthcare journey of each participant, plotted out by the diagnostic, administrative, therapeutic and consultative healthcare events, inclusive of stakeholders, that each participant encountered. As a research construct, categorising and coding can be identified by any word or phrase that “symbolically assigns a summative, salient, essence-capturing and/or evocative attribute” (Saldana 2012:3) to the data. Open coding of each segment of each data set determined data that were relevant to the research question and established core categories. Axial coding and repeated sub-coding (Gibbs and Taylor 2010) organised and distilled the relevant material, exposing similarities, differences, frequencies, sequences, causations and correspondences in the data (Saldana 2012). Out of the patterns and anomalies that were generated, key thematic features of patient journey narratives were made visible.

Some operational a priori categories for data management were established for the first construct, grounded analysis, based on potential intersecting events and participant perceptions; these were developed as relevant categories prior to data collection and became the guide for focused data analysis (Bailey 2007) during and also after data collection. Table 18 outlines the core a priori categories.

**Table 18:** A priori categories in the first construct analysis

Description from participant / researcher	Health event	Medical event	Administrative event	Non-specific event
Date				
Setting				
Overall response				
Disparity with expectations				
Effect on expectations of future events				
Effect on sense of self				

The key features and themes that emerged from the data were mapped to the participants’ clinical trajectories, creating a progressive narrative overview that

synthesised the events of clinical care with the participants' 'real-time' observations of their experiences of care. The overview was textual and also visually represented.

## Second order construct

In the second construct of analysis, the key plot points of the literary journey narrative were categorised and coded a priori and 'turning points' in the plot structure were established as sub-codes for the analysis of data. As an overview of the process, the emergent themes of the phenomenological data were mapped to the narratological themes and features of the archetypal journey narrative in order to identify a meta-narrative of patient journey. Table 19 outlines the a priori categories and coding identifiers from the literary narrative that is used.

**Table 19:** Plot categories and codes adapted from the quest journey narrative

CORE CATEGORIES	DATA CATEGORIES	TURNING POINT
ORDINARY WORLD	The establishment of the circumstances of the central character prior to disruption.	Set-up
	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.	1st turning point: The call
	The protagonist meets a mentor who provides support to move into the special world.	2nd turning point: Crossing the threshold
THE SPECIAL WORLD	There is now no turning back. The protagonist faces physical and psychosocial challenges and tests the alliances of strangers.	3rd turning point: Road of trials and obstacles:
	Now deep in the special world, the protagonist must confront death.	4th turning point: The ordeal
'NEW NORMAL'	The critical period is over. Though danger still lurks, and there may be fear about the future, the protagonist can move forward.	5th turning point: The road back
	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.	Final turning point: The return

## Analysis software

The coding software NVivo10 was used to process the majority of data collected from this project. The advantage of using software to facilitate data management was chiefly the wrangling of data. The coding process was complex, moving between: i) trajectories of events viewed from the sometimes differing perspectives of the participants, their oncologist and me; ii) the reflections, thoughts, emotions and interactions of the participants, and iii) the biomedical occurrences of disease progression and the impact of surgeries and chemical treatments. Bailey has noted that analysing data can take as



long as generating it (Bailey 2007:140). Analysis software offered extensive options for thematic coding and pattern retrieval, for visualisation and for drawing conclusions.

### Conclusion data analysis

Data analysis occurred throughout the fieldwork period and into a discrete data analysis period after the completion of data collection. Coding was the primary function by which data analysis was conducted. In the first construct of analysis, open and axial coding was used to develop emergent themes that characterised each participant's journey. From these themes, commonalities and differences, conclusions were drawn about the features of patient journeys that characterise a meta-narrative of patient journey for people diagnosed with malignant melanoma. In the second construct of analysis, the emergent themes of the first construct analysis were mapped to the phases of the socio-literary transformation narrative plot structure, in order to see if a different viewpoint on the melanoma patient journey becomes visible. The events and processes of this part of this two-part study are laid out in Table 20.

**Table 20:** The architecture of the ethnographic section of the study.

Phases of the fieldwork	Methodology	Methods
Phase 1: Data collection	Ethnography Narrative inquiry Phenomenology	<ul style="list-style-type: none"> <li>· Unobtrusive, 'other' observation</li> <li>· Opportunistic, semi-structured interviews at points along the clinical trajectory</li> <li>· 'Real-time' collection of data</li> </ul>
Phase 2: Data analysis	Phenomenological Narratological	<ul style="list-style-type: none"> <li>· First order analysis construct; coding begins during fieldwork; data sets formed by the healthcare events of each participant; analysis uses open and axial thematic coding; analysis seeks to establish a narrative overview representing the key features and themes tracked to the participant's clinical trajectory.</li> <li>· Second order analysis construct; coding begins after first order analysis is complete; data sets, categories and codes formed by phases of the hero journey narrative; analysis seeks to establish commonalities and disparities between key features that emerge from the data and the key features of the hero journey model.</li> <li>· Use of analysis software</li> </ul>

### 3.6 Implications of the study

Reframing patient journeys as meta-narratives in healthcare discourse—moving the orientation of 'patient journey' from healthcare system to patient experience—may have implications for broad, 'wicked' problems in healthcare. Patient journeys framed as lived narratives may:

- provide opportunities for healthcare system designers and clinicians to gain greater insight into the personal challenges patients face across the whole journey, from diagnosis to outcome, so that they can design more relevant services
- become vehicles by which prospective patients can predict and prepare for their

experiences so that they may engage in decision-making with informed confidence, and make more erudite choices about treatment and self-care

- advance the dialogue between healthcare and the humanities that is encapsulated in the discipline of medical humanities.

### **Narratology meets phenomenology in a meta-narrative of patient journey**

As identified in Chapter 2, the emerging discipline of medical humanities and the study of illness narratives is unpacking the potential of narrative—in literary and other fictional and autobiographical forms—to make new and succinct representations of the experience of patienthood. Narrative models identify and distinguish particular processes and structures in storytelling, and comprehend the intertwining of psychosocial and temporal journeys in stories of personal experience. To this end, narrative representations in healthcare are increasingly explored as a means of understanding how people experience and communicate about ill health and patienthood (Gale, Mitchell et al. 2003, Kalitzkus and Matthiessen 2009, Charon 2012, Coulter and Locock 2014).

Investigating the relevance of an archetypal literary narrative to data on patients' care experiences collected in fieldwork may make a specific contribution to the understanding of patient experience. By mapping the emergent themes and features of patient journey data sourced from phenomenological research to the narratological understanding of personal journey framed by the literary narrative plot structure, it may be possible to develop a meta-narrative of patient journey. This meta-narrative could circumvent the difficulties for researchers in gathering rich data on the complex, longitudinal patient journey experience that takes place across fragmented sectors of healthcare. By locating the patient as both story-teller and central character in the narrative of their journey, and offering a basic model of personal journey that resonates across ages, nationalities and personal contexts, the literary narrative plot structure could provide a suitable framework on which researchers and patients themselves can 'hang' their subjective experiences. A conceptual paper on this idea is presented in Chapter 8. As a companion tool to cross-sectional patient satisfaction measures, a meta-narrative that enables researchers to gather data on patients' trans-system journeys could contribute fresh insights into the transitions between community, diagnostic, treatment and rehabilitation environments.

## **Part Two**

Chapter 4: Can I still get a tattoo?

Chapter 5: The plot thickens

Chapter 6: I wanted this crap out of me!

Chapter 7: A close reading of melanoma illness narratives

Chapter 8: Patients as story-tellers of healthcare journeys

## The study

Though there is a dearth of qualitative knowledge about melanoma patients' perceptions of their healthcare experiences, undertaking another study may only be of value if the contribution to policy and practice is understood. If we have learned anything from the piles of data that lie dormant in academic databases it is that we need to be able to *do* something with the findings of our research. Before proceeding, the question has to be asked, 'why do this work?' There is an obligation to consider not only the contribution of the study findings to qualitative knowledge about patient experience, but to consider the epistemological foundation-making function of the study, so that it might have meaning for all who work with melanoma patients, and also for other researchers engaged in this work. This study strategy takes those issues into consideration.

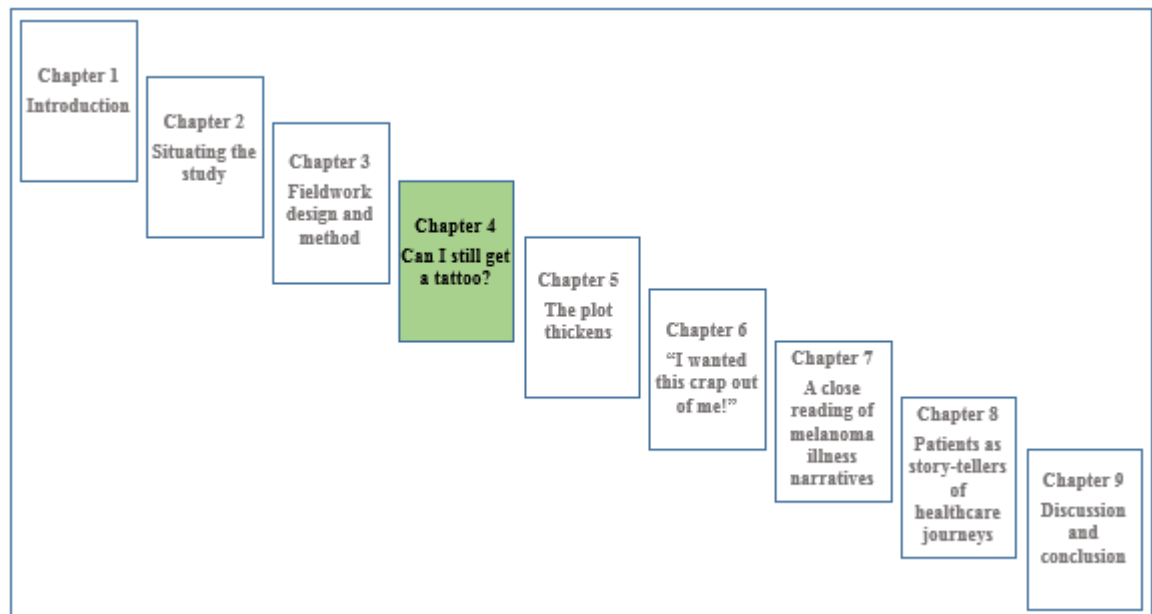
The study is underpinned by the cross-disciplinary set of precepts identified in Chapter 2 that form a methodological nexus between social science narrative inquiry, narrative medicine and medical humanities. The study adopts a triangulated approach to methods of data collection and data analysis in order to represent these cross-disciplinary frameworks for investigating melanoma patient experience. It employs the methods comprised in this set that enable inquiry into both content and structure (Czarniawska 2010) of the narrative texts produced in the research.

The four projects of the study involving two study populations, represented in the chapters that follow, each comprise one or more of those precepts and methods. The intent is to be thorough in facilitating meta-narrative views of melanoma patient journeys. The emphasis on overarching views, as noted in Chapter 1, is grounded in the context of patient-centred perspective. From that perspective, healthcare is transitory, progressive and longitudinal. The healthcare experience unfolds with the management of the disease. The rationale for conducting a study that investigates and represents the whole-plot patient perspective is that it produces knowledge of significance to policy-makers and practitioners of patient-centred care. The study fills gaps in qualitative knowledge of melanoma patients' experiences of care and does so in a way that promotes the delivery of patient-centred care to melanoma patients.

As noted, the chapters that follow are presented in the form of academic journal articles currently under peer review. I include the submission notifications. A fifth journal article finalises the study with the exploration of a narrative model by which patients can articulate their healthcare journeys.

## 4. “Can I still get a tattoo?”

**Insights into patients’ experiences from a dynamic narrative approach: A triangulated qualitative study of people with advanced melanoma**



This chapter represents a study of the healthcare experiences of a small group of people with advanced stage and metastatic melanoma as they moved through sequences of medical management. The title refers to a question one of the study participants asked his oncologist after the removal of most of the lymph glands in the arm he had planned to tattoo. The themes of patient experience identified in this chapter are framed within an overarching narrative structure that features the perceptions and reflections of these patients over time.

**Sociology of Health and Illness**



**"Can I still get a tattoo?" Insights into patients' experiences from a dynamic narrative approach: A triangulated qualitative study of people with advanced melanoma**

Journal:	<i>Sociology of Health and Illness</i>
Manuscript ID	Draft
Manuscript Type:	Original Article
Subject Area:	Narrative method < METHODS AND METHODOLOGY, Cancer < RESEARCH AREAS, Experience of illness < RESEARCH AREAS
Abstract:	<p>Shaping medical and healthcare services to meet the physical and psychosocial needs of people with melanoma requires rich, experiential knowledge of their progressive experiences of care. Using a conceptually narrative framework, we conducted a qualitative study investigating the medical and healthcare experiences of seven people attending a medical oncology clinic at a large, public tertiary referral centre in Sydney, Australia. Our results identified a meta-narrative comprising sets of medical events, within which experiences of significance to participants were explored, and thematically framed. A distinguishing feature of the narrative meta-structure was its circular progression, representing the disease recurrence that informs the experiences of people with melanoma. Our results featured: the perceptions that drove or delayed the seeking of medical attention; the physical and psychosocial impacts of investigations and diagnosis; the priorities that shaped decision-making about treatment; and the experiences that characterised ongoing disease surveillance. This study fills a gap in our understanding of how people with metastatic melanoma experience medical events, and contributes a methodological approach that narratively renders individual experiences in order to expose collective implications.</p>

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## **“Can I still get a tattoo?” Insights into patients’ experiences from a dynamic narrative approach: A triangulated qualitative study of people with advanced melanoma**

### **Abstract**

What we know of melanoma patients’ experiences of care increasingly informs the services we provide, which in turn shapes melanoma patients’ experiences of the disease. Matching services to patients’ physical and psychosocial needs requires rich, experiential information about the impact and implications of medical events from the patient perspective. Viewed from that perspective, experiences of medical events unfold as progressive narratives involving multiple clinical settings and numerous interactions with clinicians and other healthcare providers. Using a narrative conceptual framework, we conducted a qualitative study investigating the medical and healthcare experiences of seven people attending a medical oncology clinic at a large, public tertiary referral centre in Sydney, Australia. Participants were recruited and ethnographically shadowed over a six-month period, from December 2015 to May 2016. Interviews with participants were conducted through to September 2016 year. The interviews were semi-structured, and scheduled responsively to the evolving health circumstances and personal needs of individual participants. Our results identified a meta-narrative comprising progressive sets of medical events, within which experiences of significance to individual participants were explored, and thematically framed. A distinguishing feature of the narrative meta-structure was its circular progression, representing the disease recurrence that informs the experiences of people with melanoma. Thematically, our results featured: the perceptions of disease and healthcare that drove or delayed the seeking of medical attention; the physical and psychosocial impacts of investigations and diagnosis; the priorities that shaped decision-making about treatment; and the experiences that characterised ongoing disease surveillance. Our results included typologies of relational care identifying participants’ perceptions of the roles played by clinicians and other healthcare providers. This study fills a gap in our understanding of how people with metastatic melanoma experience medical events, and contributes a methodological approach that narratively renders individual experiences in order to expose collective implications.

## INTRODUCTION

Patients experience the events of medical care as emergent, compounding narratives that involve transiting, and revisiting, multiple clinical settings, and interacting with various clinicians and other healthcare providers. To comprehensively and authentically give voice to patients' perspectives, our research needs to reflect the healthcare narratives that patients live. Without this view, we suffer from a poor conception of how satisfactory and unsatisfactory care experiences map to particular points on care trajectories. The result is that we struggle to create services that correspond with patients' needs (Richards, Coulter et al. 2015). This paper investigates the insights that can be gathered from a narrative approach to understanding patient experience.

Our study engaged with the healthcare experiences of people with malignant melanoma. There is evidence that while the incidence of cancer overall is decreasing, cases of melanoma are increasing (Banerjee, Lao et al. 2016). In its rising prevalence, and also in light of the multitude of services and healthcare settings people with advanced and metastatic melanoma will encounter in the progression through diagnostic pathways to treatment, follow-up and palliative care, melanoma can be conceptualised as a chronic public healthcare problem (Cornish, Holterhues et al. 2009, Joshua 2012, Sandru, Voinea et al. 2014). Yet people's experiences of healthcare in melanoma are under investigated (Barker, Kumar et al. 2011), and when they are researched, cross-sectional rather than longitudinal studies dominate.

Few qualitative studies focus on the discrete experiences of people with metastatic melanoma, and to our knowledge there are no primary studies that have investigated personal experiences of the healthcare delivered to people with advanced stage and secondary melanoma in the full framework of their trajectories. Knowledge of the entire melanoma patient journey, with its specific complexities, subtleties, and scientific and social-scientific nuances, is lacking (as it is for patients with many other conditions). This paper sought to fill the gap. We shadowed patients ethnographically and collected semi-structured data from patients' descriptions and reflections of the progressive clinical, organisational and logistical events they experienced throughout their care. We used grounded, thematic analysis to develop findings, which we then related by discussion to the key objectives of patient-centred, or person-centred, care (PCC).



## **Background**

The incidence of malignant melanoma in Western countries is rising at more than three per cent annually (Whiteman, Green et al. 2016). The treatment for melanoma depends on the stage in which it is diagnosed. Where possible, surgery is the first line of treatment, with excision of the primary tumour and where needed, the lymph nodes involved with the disease. The resulting collateral damage of scarring and lymphedema impose life-long burdens of physical and psychosocial care on patients and health system, in addition to the 'payloads' of ongoing surveillance programs (Watts, Dieng et al. 2015). There are advancing therapies for people with metastatic melanoma (Robert, Karaszewska et al. 2015), such as immune-boosting drugs, and targeted drugs for patients with features such as a mutation in the gene that encodes the B-Raf protein kinase. If diagnosed when it is metastatic, melanoma is considered to be incurable (Hill, Robinson et al. 2015).

With growing awareness of melanoma, greater numbers of people are diagnosed in the earlier stages of the disease. However metastatic melanoma has a different, more complex diagnostic profile that places a discrete burden on healthcare systems and patients. 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 which, characterises metastatic melanoma, may not be picked up until serious physical manifestations are present. Further, there is confusion over guidelines for ongoing surveillance for high-risk patients, with poor alliance among healthcare providers as to how long surveillance should be maintained, and what scanning technologies should be used (Danielsen, Højgaard et al. 2013, Marciano, Merlin et al. 2014). Thus the diagnostic pathways for people with melanoma can be delayed and indirect, and involve numerous health services beyond the dermatological domains of care associated with early stage melanoma.

## **Aims**

Our study set out to appreciate the challenges of the healthcare situations encountered by a population of people with metastatic melanoma. Satisfactory healthcare experiences are viewed as both a right, and an economic imperative. When people feel their personal preferences have been attended to and they have been provided with all the information they need to make decisions, they have greater ownership of their own care, and their overall health outcomes are

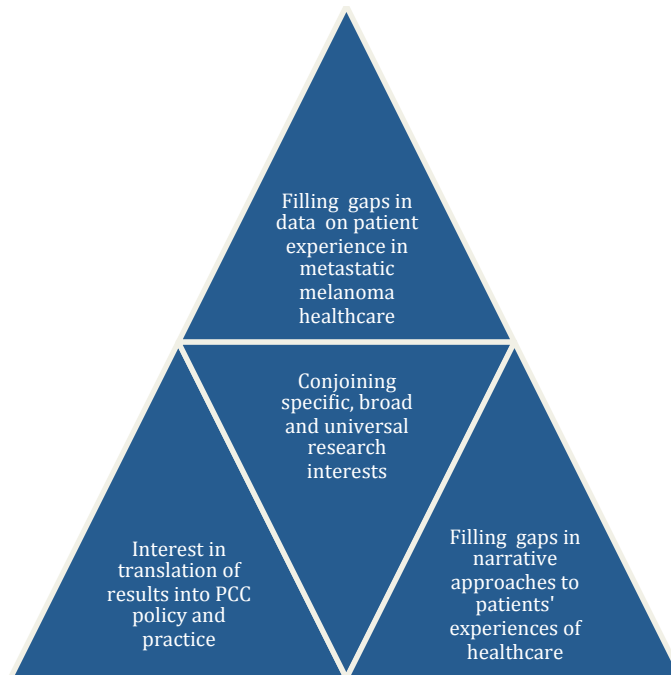
potentially higher than if they have had unhappy experiences (Doyle, Lennox et al. 2013). Consequently, patient experience data are increasingly valued as a knowledge base for improving the quality of care that is delivered (Ziebland, Coulter et al. 2013).

In the main, patient experience research is undertaken for two overarching purposes: to investigate patients' experiences in relation to organizational criteria for quality care—collecting data grounded in what providers want to talk about; and to investigate patients' experiences in relation to their own criteria for quality care—collecting data grounded in what patients want to talk about. Our study undertook the latter; we aimed to qualitatively investigate participants' experiences of care, as defined and framed by them. In response to growing concerns about the translation of evidence into policy and practice (Coulter and Locock 2014), we extended the interests of the study to a consideration of how the results might relate to essential PCC objectives.

While PCC is defined and its objectives identified variously in literature and healthcare policy, there are core aims that underpin all PCC rhetoric (Kitson, Marshall et al. 2013). These centre on the provision of “personalised, responsive and compassionate care” (Bridges, Hughes et al. 2015, Churchill 2015), in both organizational and dyadic streams (Liberati, Gorli et al. 2015), an objective of which is to imbue patients with actual and perceived power in the co-production of their medical management (Parish 2015). The end-goal of PCC implementation is for patients to take responsibility for their own care, both in relation to preventative behaviours that will keep them from needing healthcare, and also in relation to follow-up behaviours that will enable them to efficiently manage consequences of illness and treatment, and chronic conditions.

The study thus took shape around a triangulated rationale (see **Figure 1**) in which we engaged with: filling the gap in data on patient experience in melanoma healthcare; filling the gap in progressive, narrative research on patients' experiences, and; attending to the potential translation of study results into PCC-shaped policy and practice.

**Figure 1:** The triangulated approach that underpinned the collection and analysis of data.



## **METHOD**

### **Participants**

The participants for this study were drawn from a population of people attending a generalist medical oncology clinic at a public Sydney tertiary referral centre. The 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 malignant melanoma, over 18 years of age and English-speaking. There were no exclusion criteria regarding demographics or definite stage of melanoma. The period of recruitment was six months, from December 2015 to May 2016. Potential participants included patients attending the clinic for the first time or were ongoing patients of the clinic. Although patients were attended to by several doctors and specialists, all potential participants were patients of one medical oncologist.

### **Recruitment**

Potential 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 researcher to discuss the study further. If the patient agreed, the researcher would meet the patient separately without the oncologist to describe the study in detail and seek

informed consent in order to minimize the risk of coercion. In total, nine (9) participants agreed to join the study and to the publication of de-identified study findings, however, highlighting the risks of the disease and its challenging course, two died before they could take part with the interviews. To alleviate any potential burden to patients due to the research activities, the initial active involvement required of participants to take part in the study was restricted to one interview of at least 20 minutes in length. Participants were also asked to allow the observational presence of the field researcher (KL) during clinical consultations and treatments, and to ongoing interviews either in person in a setting of their choice, or by phone. Six of the seven participants consented to observation of consultations and treatments in addition to interviews.

A variety of involvement events took place thereafter 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. The data collected on that participant to the point of diagnosis have been included because his perspective throughout was that he had melanoma, and so the experiences he underwent and was describing were from the point of view of someone with melanoma.

### **Participants' characteristics**

We present in **Table 1** 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 <sup>22</sup>	Melanoma/ tumour	Since last 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 & 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 identified in first surveillance scan after melanoma on back 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

The data set for each participant comprised the transcripts of interviews with participants, the observational notes of the field researcher, and the medical information about the participant contributed by the supervising oncologist for the study. The intent of data collection was to form narratives that describe what happened as each participant pursued the compelling goal of resolving the threat to their lives posed by malignant melanoma.

During each interview with a participant, a semi-structured approach to both process and content was undertaken. An interview guide was developed with questions that intended to open dialogue and allow participants to move between 'question and answer' mode and 'storytelling' mode with the aid of prompt

<sup>22</sup> TNM staging system classifies cancer stages according to an alphanumeric system.

questions used to engage the participants into more complex responses and ‘content probe questions’ to develop particular issues and themes. A key word ‘journey’ was used to communicate that the study was interested in the past, present and imagined future of their healthcare experiences—their personalised narrative. This framing of the research relationship was intended to achieve a more emic than etic attunement to the interests of the study (Holloway and Wheeler 2013:161), though the tensions between the two are acknowledged (Olive 2014).

## **Analysis**

The data set comprised transcriptions of recorded interviews with participants and their carers, handwritten records of interviews with participants and their families (in situations in which recordings had not been approved e.g., while in chemotherapy clinics), medical status and profile information on participants supplied by the oncologist, and observational notes made by the researcher. The data were downloaded into the software package NVivo10 (QSR International). Analysis was based on the thematic analysis guidelines defined by Braun and Clarke (Braun and Clarke 2006). Their guidelines do not offer specific means of analysis but rather entreat that each study should provide a clear analytic rationale for why the analyst is gathering particular data into thematic sets, and how those choices relate to the research question. In this study, we defined a theme as a topic, represented by participants through description or reflection, which was instrumental in shaping the healthcare experiences of one or more participants.

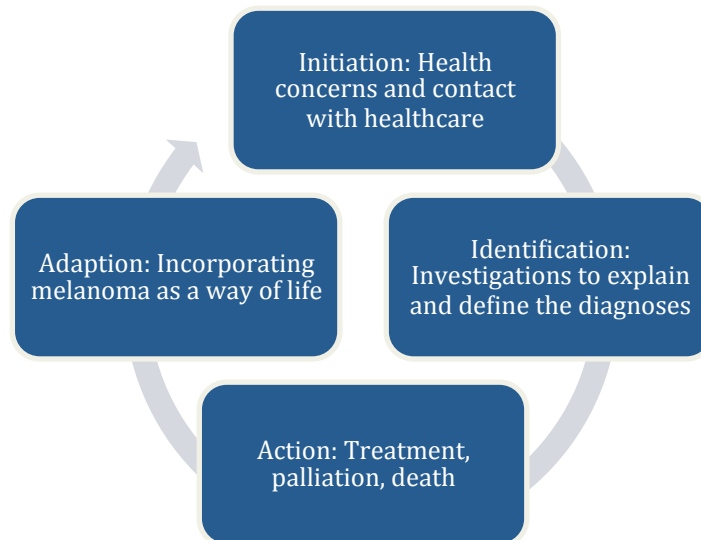
## **RESULTS**

In the analysis of progressive events described by participants and observed by the researcher, a meta-structure emerged, characterising a collective narrative of the points at which care experiences and perceptions of care intensely affected people throughout their illness journeys. A key feature of this narrative meta-structure, which is represented in Figure 2, was its circular rather than linear progression, with some participants experiencing a cycle of recurrence. The structure is shaped around four key segments that are examined in detail in this section:

- Initiation: Health concerns and contact with healthcare
- Identification: Investigations to explain and define the diagnoses
- Action: Treatment, palliation, death

- Adaption: incorporating melanoma as a way of life

**Figure 2:** A narrative meta-structure of melanoma experiences. This model features keys sets of events in participants' healthcare trajectories, thematically identified in four narrative segments.



## 1. INITIATION: HEALTH CONCERNS AND CONTACT WITH HEALTHCARE

As the starting point of each participant's narrative, this set of experiences is characterised by the perceptions of disease, and also of medical and healthcare practices, that informed decision-making about when to seek medical attention and why. The key experiences identified in this segment comprise the following information.

### Association between current symptoms and melanoma

One of the participants' 'storylines' at this narrative marker specifically features skin-related health issues (PC). For the other six, normal life—which for some involved ongoing management of other health conditions—was interrupted by a change in health or concern about health that bore no manifest relationship with the symptoms of melanoma that had previously brought them into melanoma care. Rather, the range of health issues that participants were dealing with at this point included confusion and forgetfulness (PA), a concern about DVTs (PB), a fall down a flight of stairs (PD), the detection of a lump on the eye during a cataract examination (PE), increasing pain from a fractured rib (PF), and stomach pain (PG). Perceptions of health urgency and personal rationalisations of the medical significance of health changes mediated participants' choices rather than any concern with melanoma.

### **Rationales for delays in seeking medical care**

Personal values and beliefs about particular health conditions informed the decisions by some participants to delay seeking health advice. PA believed that confusion and forgetfulness indicated stress, and rationalized that since stress was a temporary condition brought on by current circumstances in her life, and since the stress would go away when the circumstances changed, there was no reason to seek medical advice. PB had been told by a clinician to expect ongoing pain from his 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 dealing with complex personal issues.

### **Rationales for seeking medical care**

Personal values and beliefs about the importance of self-determined health management also feature in this narrative segment. PB, given a history of DVT and a discomfort in his left groin, organized a pre-emptive ultrasound prior to an upcoming flight. PE was adhering to a schedule of cataract surveillance appointments. PG decided that an episode of sudden and severe stomach pain, though resolved and not ongoing, was worthy of further investigation.

### **Melanoma-related healthcare history**

Of the seven participants, six had been treated for a primary melanoma, had believed they completed their surveillance programs, and had been given the 'all-clear' at the start of this narrative segment. PB had sought advice from his general practitioner for the discomfort in his left groin months earlier which he was concerned was a hernia. Since no lumps could be felt, further investigations were not carried out.

Thematically, the rationales, uncertainties, priorities and beliefs that shaped the starting points of participants' progression to a diagnosis of metastatic melanoma comprise:

- i) Low sensitivity to or awareness of melanoma recurrence
- ii) Rationalisation of health disturbances and pain leading to diagnostic delays
- iii) High prioritisation of pre-emptive health management leading to timely diagnosis
- iv) Low healthcare provider awareness leading to diagnostic delays
- v) Perception of being 'clear' of melanoma



## **2. IDENTIFICATION: INVESTIGATIONS TO EXPLAIN AND DEFINE THE DIAGNOSES**

The data characterising the next narrative segment featured a progression into the definitive healthcare events and processes that lead to the diagnosis of metastatic melanoma. These experiences are characterised by descriptions of transitions between the home environment and clinical environment, and between ‘ordinary’ life and life as a patient facing a critical diagnosis. During this segment, reflecting the sometimes complex diagnostic pathways for participants, PE was told that the initial assumption of melanoma could not be confirmed. The key experiences identified in this narrative segment comprised a range of events and experiences.

### **Physical and psychosocial impact of investigations and consultations**

Participants described a high level of logistical and time commitment in relation to appointments. PE noted that scans and consultations were scheduled “*one thing at a time*” and that it was tiring to keep up his commitments in other areas of his life. For PG, an open lung biopsy caused problems where previously there had been none: “*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.*” (PG) Participants in discomfort or pain associated with the progression of the disease, or from the consequences of biopsies and comorbid conditions described the physical difficulties of getting to appointments, and managing the movement required to undergo scans. PF, for example, described his pain as moving from a “*three*” to a “*ten*” when moving from lying to sitting to standing, and noted that getting in and out of the car to come to the hospital for appointments was very difficult and distressing for he and his wife. He and other participants were appreciative when scans and consultations were scheduled to occur in the one location or on the one day.

### **Information pathways and knowledge absorption**

Though participants showed interest in the detailed explanations of scanning equipment and visually represented results provided by clinicians and technicians, the language used by participants in their descriptions of investigative experiences reflected their capacity to understand and absorb the information and explanations provided to them by their oncologist and other clinicians. 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."* (PB) Most participants did not conduct research beyond the information provided by hospital and particular clinicians. *"I'm an absolute outsider as far as medical things are concerned and 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**

The participants who were given a diagnosis of advanced melanoma expressed a desire to be given a timeframe for survival, and were frustrated when their clinicians' responses framed prognosis as a complex undertaking. They also relate their current diagnosis to the experience of having been given the "all-clear" on their previous melanoma. PB expressed 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."* PD expressed "shock" that she had been given the "all clear" and 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."* (PD). Four of the seven participants (PB, PD, PE, and PG) described previous and current diagnoses of 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."*

The vagaries of diagnosis were highlighted with concern by some participants, and noted without comment by others. PA's family noted that while one tumour had been identified as metastatic melanoma, other tumours in other parts of their mother's body were only assumed to be melanoma, and they wondered how that would impact treatment decisions. PC accepted that the enlarged lymph nodes detected in his most recent scan were not considered big enough to remove. Participant E, when told that he was no longer considered to have cancer, was

perplexed about the change in diagnosis, and uncertain as to whether the change in diagnosis was definitive.

### Relational aspects of care during investigation and diagnosis

Descriptions of participants' communication with clinicians and with healthcare providers are categorized in **Table 2** alongside corresponding meaning themes derived from analysis.

**Table 2:** Participants' representations of interactions and relationships with healthcare providers during investigation and diagnosis.

Relational themes	Examples
Doctors as deities	[To oncologist] <i>"As far as I'm concerned, you're god. Whatever you say to do, I'll do."</i> (PA)
Doctors as oracles	[To oncologist] <i>"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."</i> (PF)
Doctors as allies	<i>"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."</i> (PE)
Nurses as challenged carers	<i>"It's always a problem, my 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."</i> (PD)
Doctors as silos of care	<i>"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."</i> (PG)

Thematically, the key experiences highlighted by participants in relation to this narrative segment comprise:

- Information absorption
- Personalised preparation for the physical and psychosocial impacts of investigations
- Complex, unmanaged diagnostic pathways in metastatic melanoma
- Dissonance between patients' desire for definitive prognosis and the problems of prognosis
- Complex, nuanced interactions and relationships with healthcare providers

### 3. ACTION: TREATMENT, PALLIATION, DEATH

The third narrative segment to emerge from participants' descriptions of, and reflections on, their healthcare experiences featured a transition from investigations into sets of events that filtered out ambiguities and narrowed down treatment options. During this narrative segment, two participants died (PA and PF). These events highlight the time-critical nature of events in the medical management of melanoma, and point to the problematic issue posed for clinicians

of providing a prognosis for survival. Treatment of metastatic melanoma included systemic treatment- medications injected or ingested to shrink or control the tumours, locoregional treatment such as radiotherapy directed towards a specific problem area such as the brain or bones and palliative care aimed at minimizing the symptoms from the tumours. Some systemic treatments may be available only through clinical trials in specific locations that have strict eligibility criteria and procedures. Our findings identified four key sets of experiences within this narrative segment.

### **Treatment decisions**

A conceptual decision-making process was highlighted in the data, in which participants and their families determined what kind of approach they would take to treatment. *"Both mum and dad were clear about the fact that they will do what they need and they will do what we can."* (family of PA). Decision-making related to clinical trial participation focused on factors such as personal priorities, lifestyle and age. PB, whose son had died from melanoma and who was concerned with the familial implications for his grandchildren, was prepared to undergo any surgery advised by his oncologist and commit to any relevant clinical trial available, though he noted that *"drug trials [and] new research will not come to you. You and your family must seek out the opportunities."* PF clearly established his preference not to be involved in decision-making, saying: *"You make all the decisions for me and I go along with whatever you say."* (PF). PG expressed his approach as being one of choosing quality care and then following the directions of those with expertise.

The wait time of up to four weeks for BRAF testing 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".

The option of seeking second opinions on treatment decisions was raised by two participants. PB noted, *"People who probably don't necessarily realise that they have a choice"* (PB). 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."* (PG)

### **Information pathways and knowledge absorption**

Though participants commented that proto-oncogene B-Raf (BRAF) gene mutation testing had been explained well to them, five of the seven made no reference to 'BRAF' in their descriptions of their circumstances, instead making references to 'the test' or reflecting an 'on-off switch' 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 course of tablets for treatment and immunotherapy as a course of injections or "chemo" therapy: "*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.*" (PD) Participants also described positive preparation pathways for immune-therapy treatments, involving information pamphlets and tours of treatments facilities.

### **Physical and psychosocial experiences of treatment**

Our enrollees varied in their concern with the side effects of treatments. Hair loss after radiation to the tumour on her skull was described as a minimal concern for PA. PD was satisfied that the "*lumps*" and "*red marks*" on her arms and legs were "*routine for the treatment.*" 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. On the clinical trial for Dabrafenib, PB suffered almost immediate side effects of curly hair, additional layers of skin on his feet that had to be "*shaved off*" every six weeks, body aches, and fatigue which he rationalized against the fact that his tumours were shrinking significantly.

The treatment process was described as "*routine*" and "*comfortable*", with the exception of the difficulties PD faced each time staff tried to insert the cannula into her veins: "*If they have to do it too many times, yeah, it hurts a little bit.*" (PD) 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

Descriptions of interactions with clinicians and experiences of care during the treatment period related to reliance on clinicians' expertise. These findings are categorized with corresponding themes in **Table 3**.

**Table 3.** Relational care during treatment

Relational themes	Examples
Doctors as bearers of treatment options	<i>"You've no idea how much hope you've given me, and all my family, because they've all just dropped their bundles ..."</i> (PA)
Doctors as bearers of patients' risk	<i>[To oncologist]: "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."</i> (PF)
Doctors as guarantors	<i>"[The oncologist] recommended this and ... he's got a good success rate apparently so there's every chance that it's going to go [right]."</i> (PD)
Doctors as curators of patient information	<i>"After the last scans [following a first round of Keytruda] 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."</i> (PG)

Thematically, the key experiences of treatment comprise:

- Establishing personal approaches to decision-making process
- Negotiating factors implicated in treatment decisions
- Managing technical and medical information
- Dealing with the demands, logistics and side effects of treatment
- Complex, nuanced interactions and relationships with healthcare providers

## 4. ADAPTION: INCORPORATING MELANOMA AS A WAY OF LIFE

Of the four participants who progressed into definitive treatment, two had transitioned out of treatment and into follow-up care as 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 lymphedema physiotherapist to ensure his leg was being well managed.

Side effects from the drug Dabrafenib initially received in a clinical trial continued to impact PB, though the addition of a second drug, Trametinib had largely

rectified the side effects of the first drug. PB rationalized the impact of side effects in relation to 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!”*

### **Disease surveillance and psychosocial management of potential recurrence**

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.”* [PB]

### **Dependence on healthcare services for personal life decisions**

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?”*

Thematically, the key experiences of this fourth narrative segment comprise:

1. managing the ongoing consequences of treatments and side effects of medications
2. managing psychosocial impact of being at high-risk of recurrence
3. dependence on surveillance technology for knowledge of own health and survival
4. continuing reliance on clinicians to make decisions about personally significant matters

## **DISCUSSION**

The aim of this research was the identification and exploration of progressive personal healthcare experiences along trajectories of care. With the second and third narrative segments representing the critical periods of participants’ healthcare trajectories, these segments were characterised by yields of rich data, by way of contrast to the ‘bookends’ of the first and fourth segments.

### **First narrative segment**

Notwithstanding the volume of data and the richness of the datasets, the first segment registered the gateways of participants into their condition, featuring their earliest responses and confusions about their health, and then orientation towards the identification of cancer. The links between a health disturbance or pre-emptive concerns about health and melanoma are not yet manifest,

highlighting the complexity of diagnostic pathways related to metastatic melanoma. Also highlighted are key PCC issues relating to responsiveness to patients' needs for information and education about metastases from melanoma. Participants gave no indication of being sensitised to personal fragilities and higher candidacy for secondary cancers, or knowing what symptoms might signify metastases.

### **Second narrative segment**

The second narrative segment featured issues of direct relevance to PCC objectives, characterised by the varying capacities of individuals to absorb the information provided by their clinicians, the psychosocial implications of melanoma recurrence, and issues relating to perceptions of control over healthcare events and processes. The need for individualised compassion and responsiveness in the delivery of medical care was particularly highlighted by participants' concern with the physical and logistical demands of appointments and consultations, and participants' responses to the uncertainties associated with diagnosis.

Prominent in both the second and third narrative segments were subsets of content focused on relational care, and the way that participants perceived interactions and relationships with healthcare providers. The tenor and sub-strata of the interactions that emerged from our analysis ranged from preferences for non-collaborative decision-making in which doctors are perceived as all-knowing deities, through to perceptions of doctors as allies, mentors, and oracles in decision-making processes. The findings underpin the need for PCC approaches to encompass complexities and textures in relational care, and also point to deeper interests related to participants' beliefs about the roles of healthcare providers, and relationship dynamics between patient participants and their healthcare providers.

### **Third narrative segment**

A prominent PCC issue relating to compassionate care for people with metastatic melanoma was raised in the third narrative segment, focused on participants' frustration regarding long wait times for BRAF results: the wait times for BRAF test results contrasted with participants' perceived urgency of forming decisive pathways for the management of the disease, creating a 'hurry up and wait' dynamic in the narrative of people with metastatic melanoma. Our results suggest there is an opportunity for further exploration of BRAF testing as a key instrument



in shaping the healthcare experiences of people metastatic melanoma. A further concern relating to patient-centred care in melanoma healthcare delivery focused on responsiveness to surveillance time frames; diagnosis occurred after surveillance programs had been completed—sometimes just weeks after participants had been given the ‘all clear’—pointing to issues in timeframes for follow-up care. Matters relating to compassion and responsiveness were also raised in regard to continuity of care, with one participant let down by lack of promised support from a palliative care team, and another informed months after his diagnosis that he had tumours he had not been told about, presumably because there were not of relevance to his healthcare providers.

#### **Fourth narrative segment**

The last phase in the circular pathway from health disturbance through diagnosis and treatment was the transition into prolonged life, back in the patient’s ‘ordinary’ world. As noted, two of the seven participants who took part in the study moved into this phase of the collective narrative by the study’s completion date (PB and PC). PA and PF had died. PD and PG were still going through treatment, and PE had had his diagnosis changed. This final narrative segment, then, offers the insights of two participants’ experiences of the chronic reliance on healthcare services implicated in their survival from metastatic melanoma. In this segment, two key PCC domains emerge as relevant: personalised 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.

#### **The study in context**

Our finding that the collective healthcare experiences of our participants may be modelled as a cyclic meta-narrative highlights the need for attention to whole-care patient journeys, inclusive of preventative and follow-up practices, and strong information and awareness pathways relating to metastatic melanoma. The thematic subsets of participants’ experiences furnish relevant information for both healthcare professionals working in melanoma care, and patients themselves, about the impact of medical care, in contrast to the impact of ‘having’ the disease. The themes identified in our analysis point to an interchange between the way people perceive personal control over circumstances in their ordinary states of health and the capitulation of control in disease management. This is characterised by the technological identification of tumours in people who had no perceptible

symptoms, the deferment of treatment decisions until BRAF test results were returned, and questions participants asked about their bodies and their lives that could be answered only by their physicians. Conversely, the results identified the burdens of responsiveness to individualised needs carried by clinicians working in melanoma care. Further, in delivering a set of documentary analyses of patients facing potentially life-threatening events over segments of care, the results provide a typology that conceivably has merit beyond the sphere of patient experience particular to melanoma, and into the wider understanding of the nature of relationships between healthcare providers and patients with critical diseases.

## **LIMITATIONS**

We believe this to be the first study to locate patients' experiences of metastatic melanoma healthcare as a set of progressive responses to key phases in their healthcare journeys. A limitation of this study is centred on the small size of the participant group, which makes thick, rich experiential data available for inspection and facilitates understanding of care from multiple patients' vantage points, but limits the extent to which the data can be said to represent the narrative structure of healthcare journeys for other people with advanced melanoma. However we believe the test in studies of this kind to be credibility: are the involvements a credible account of the ensemble manner in which patients enter, encounter, traverse and conclude their interfaces with the healthcare, mediated by their disease? We believe they are. A further limitation relates to nature of the collection of data, which was necessarily ad hoc and adaptive to each participant's state of health, living situation and availability; this created a variable data set per participant, inclusive of recorded interviews, handwritten observational notes, and oncology reports. The wide range of communication skills shaped the richness and extent of the data. Finally, given the health situations of the individual participants, the narrative approach taken in this study did not accommodate comorbid illness trajectories.

**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.

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wrote the first draft. MC contributed to and edited the content of the manuscript. JB contributed advice along the complex research journey from initiation to conclusion, and participated in developing drafts with the addition of appropriate ideas and editing. All authors contributed to and approved the final manuscript.

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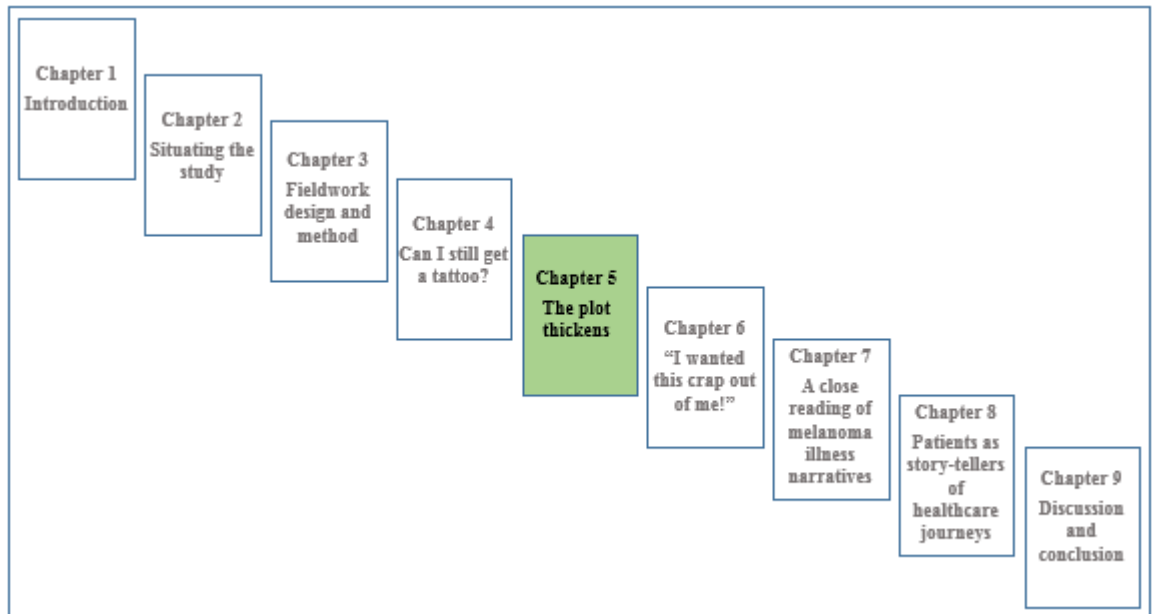
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## 5. The plot thickens

### Archetypal narrative structure in the melanoma patient journey



This chapter emplots the healthcare journeys of the study population featured in the previous chapter according to the plot structure of the archetypal quest narrative of journey and transformation. This view of patient journey identifies the turning points in healthcare experiences that move the journey along its narrative arc.

## Medical Humanities

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

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

### **Abstract**

In this paper we present a multi-disciplinary approach to the empirical investigation of patients' experiences of healthcare. We bring together patient journey mapping, narrative inquiry and literary analytic frameworks. The central 'characters' of our study are people with melanoma—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. Our findings identify the potential of this analytic framework as a flexible methodology for the representation of the outset-to-outcome melanoma patient journey.

### **INTRODUCTION**

In the normative narrative of patient-centred 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 et al. 2013) patient-centredness. Patients still tell of being treated as secondary characters in a healthcare provider's sub-plot. The narrative remains more normative than lived.

This paper empirically examines a healthcare narrative in which there is one 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 the plot structure of the archetypal journey narrative.



## Background

Knowledge of patients' experiences is a key evaluation strategy in the efforts to provide quality care (Doyle, Lennox et al. 2013, Richards, Coulter et al. 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—the silos of care—however they form an experiential 'set' for the patient. This set can be conceived, in literary terms, as the narrative of patient experience. It features the patient as the central character because it takes the patient point of view by representing all parts of the patient journey.

Qualitative researchers who are concerned with the "narrative knowing" (Polkinghorne 1988:111) of patients' healthcare experiences collect stories from patients that "capture the singular, irreplicable, or incommensurable" personal meaning (Charon 2006:45) conveyed in 'thick, rich description' (Geertz 1973:3). The stories patients tell about the progression of events and processes they experience in healthcare can be plotted to comprehend the whole storyline of patient experience. This idea is reflected in the use of patient journey mapping (Trebbles, Hansi et al. 2010, Martin, Biswas et al. 2014). 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 et al. 2008). In this conception, the patient's point of view is again central because only patients are privy to the whole journey. However patient journey mapping does not engage with the rich experiential accounts formed in narrative inquiry.

In this paper we present a multi-disciplinary analytic approach that meshes longitudinal patient journey mapping and narrative inquiry with the precepts of literary analysis. We bring together conceptions of patient experience as biopsychosocial-medical, organizational and dyadic phenomena (Liberati, Gorli et al. 2015) and the idea of representing patient experience as a narrative. The central

characters of our study are people with melanoma—a disease that makes heavy, longitudinal demands on patients and healthcare resources. With its rapidly rising incidence around the world (Trakatelli, Siskou et al. 2012, Walter, Birt et al. 2014) and its wide demographic profile, melanoma is a ‘healthcare disease’—it cannot be diagnosed or treated without the use of extended healthcare services, and survival depends on ongoing medical surveillance (Cornish, Holterhues et al. 2009).

Primary melanoma refers to an original tumour on the skin. The term ‘early stage’ melanoma describes a situation in which the tumour is confined. The goal of treatment is cure, which is most often achieved by surgical incision of the tumour and sometimes associated lymph glands. Melanoma may spread through the blood stream microscopically, or metastasize, eventually manifesting as tumours in parts of the body distant to the skin. The finding of this distant tumour implies an advanced stage of melanoma that is seen as incurable. 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 et al. 2014:252). However, the healthcare trajectories of people with advanced and metastatic melanoma are poorly investigated (Stamataki, Brunton et al. 2015:780). Our study addresses this gap in the literature.

## **METHOD**

### **Recruitment**

Over a six-month period people with melanoma, or suspected melanoma, attending a medical oncology clinic that was part of a public tertiary referral hospital in Sydney, Australia, were approached to consider their participation in the study. They were all patients of one medical oncologist who made the first contact in relation to the study. Potential participants were approached if they were English-speaking and over the age of 18 years. They were told that the study was interested in the 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 consultation 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 between December 2015 and May 2016.

## Participants

The population of potential participants comprised people with confirmed advanced stage tumours or clues to suggest advanced stage tumours. All but one had previous melanomas. 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). 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+

## Data collection

**Conceptualisation:** Data were collected up until October 2016. The semi-structured interview is a universal instrument of qualitative research in general (Englander 2012:13) 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 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. Based on the list of

open-ended phrasing defined by Charmaz (Charmaz 2014), 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.

**Process:** Over the period of involvement, the interviews and observations were organised 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 her family which occurred prior to, during and after the diagnostic consultation in the oncologist’s rooms. Thereafter a metastatic brain tumour 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. As the participant was incarcerated at the time of agreeing to be part of the study, 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 tumours 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.

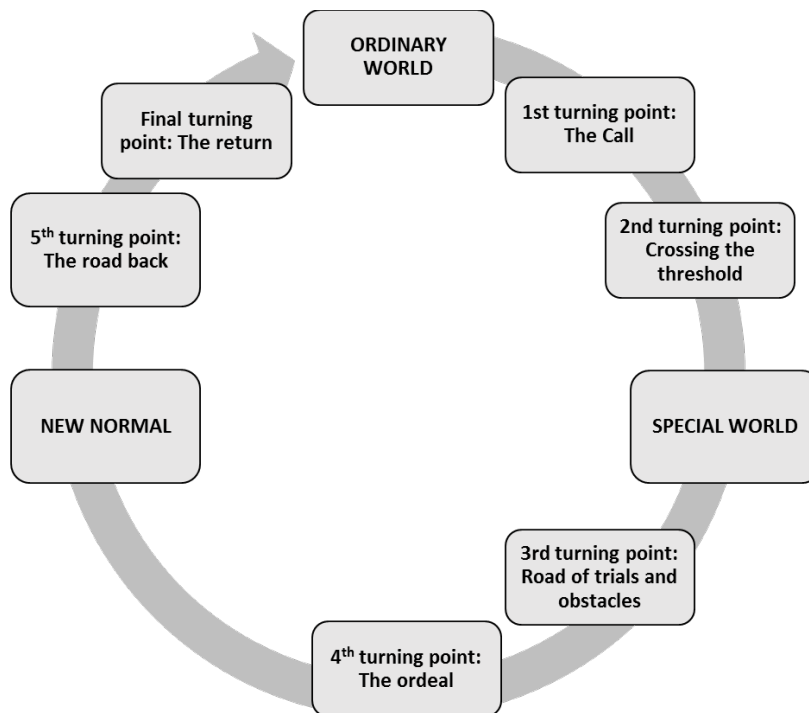
As participants did not enter the study until after their diagnosis of tumours, the data collected on their patient journeys prior to that time was retrospective. Thereafter the data set comprised descriptions by patients and their carers of their experiences given in interview, notes taken by the researcher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

## **Analysis**

The personal journey narrative we employ in analysis was identified by sociologist Arthur Frank as a narrative mechanism commonly identifiable in the 'telling' of illness (Frank 1998). The specific narrative framework we used in analysis was based on the archetypal transformation plot identified in deconstructions of personal journey narratives by analysts of mythology, fairytales and films (Campbell 1949/2008, Propp 1968, Vogler 1992).

Though typologies of plot structure vary according to the interpretation of the archetypal transformation narrative, there is a common framework (see Figure 1): the protagonist is compelled by disruptive circumstances to move from his or her ordinary world into a special world that presents physical, psychological and/or emotional challenges, and which at worst threatens the protagonist with death. Survival enables the protagonist to move from the special world into a 'new normal'. As the protagonist progresses through these turning points, he or she encounters allies and antagonists. Within this broad structure, there are seven key plot points. The progression of the central character plot through these plot points is driven by 'turning points'—a narratological phrase describing events that move a narrative in a new direction (Hühn 2013:16).

**Figure 1:** The archetypal transformation narrative, adapted from the models first produced by Campbell and then by Vogler (Campbell 1949/2008, Vogler 1998).



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 categorised thematically according firstly 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 (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.

## FINDINGS

### 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 50<sup>th</sup> 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 organising 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 organises 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 til 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 was 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 tumours 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 tumours to be secondary melanoma.

### **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 tumours 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 organises a BRAF test and a PET scan to investigate the changes on PF's second lumbar vertebra and to understand whether other tumours 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.

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

**PA:** After undergoing radiation therapy for the tumour in her skull, PA suffers seizures from the brain tumour, 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 tumours and shrinkage of others. He is put on a second course, which was continuing at the time the study was completed.

### **'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.*

**PB:** On Dabrafenib, there is 60 per cent shrinkage in his tumours. In conjunction with Trametinib, the tumours 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 tumours. 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.

## **DISCUSSION**

Our findings develop the visibility of the patient as protagonist of a personal biomedical trajectory set in a psychosocial framework of transition into and out of high-stake circumstances. In these cases, healthcare providers are implicit to the action, and, when identified, are positioned as secondary characters whose qualities and behaviours 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-centred, 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.

While the plot of each person's melanoma story differs according to the staging of his or her disease, and the metastatic nature of the disease, 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. While the plots of events comprise care experiences that are specific to the experiences of each participant, the archetypal transformation structure features a framework that develops an interrelationship between singular patient experiences, and patient experiences that are common.

This kind of research is deeply personal for both patients and investigators. It is threatening to patients to be enrolled in studies of this kind, and researchers enter their emotionally-charged world. There is no neutrality here: people facing life-changing events and progressing through an intimidating storyline are agreeing to participate in research, exposing their unique narrative at the very time they face unenviable trials and ordeals.

The representation of events as progressive necessarily represents unfolding time: some events included as plot points occurred prior to participants joining the study while others occurred in the realtime of the study and were observable by the research team. This points to considerations of experience as evidence, which are inherent in all narrative methodologies, but also to the responsibilities of qualitative researchers seeking to represent the beginning, middle and end of participants' stories (Connelly and Clandinin 1990:8). The choices we make about the events we include in the stories we tell are implicitly culturally informed and contextualized (Hawkins 1999, McAdams 2008, Smith 2008, Frank 2011:36, Goyal 2013). In the research setting, the choices participants make about which events to include and describe are shaped by not only by the 'normal', implicit, cultural and contextual storytelling forces, but also the explicit requirements of the researchers who ask participants to begin and end their narratives at particular points in their lives, and encourage descriptions about particular events in between those points.

The limits of this study relate firstly 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. In choosing to chronicle healthcare experiences of people with advanced stage melanoma we exposed narratives comprising complex diagnostic pathways and multiple healthcare encounters. 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, great insights into patients' lives and encounters can be achieved through research of this kind, as we show.

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 of patients as they move through their biomedical trajectory, or comprehend the progressive phenomenological experiences of being a patient (Carel and Cooper 2014), or of being a person receiving healthcare for the management of melanoma. Further, the healthcare experiences identified in the study could be the standalone subject of qualitative investigation; a researcher could choose to investigate patient experiences related to BRAF tests, or patient experiences related to excision of tissue, for example. The journey narrative analytic framework provides a flexible methodology for the longitudinal representation of care experiences.

**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).

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**Contributors:** KL designed the study, prepared the study materials, performed the participant interviews, analysed 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.

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**Conflicts:** There are no conflicts of interest.

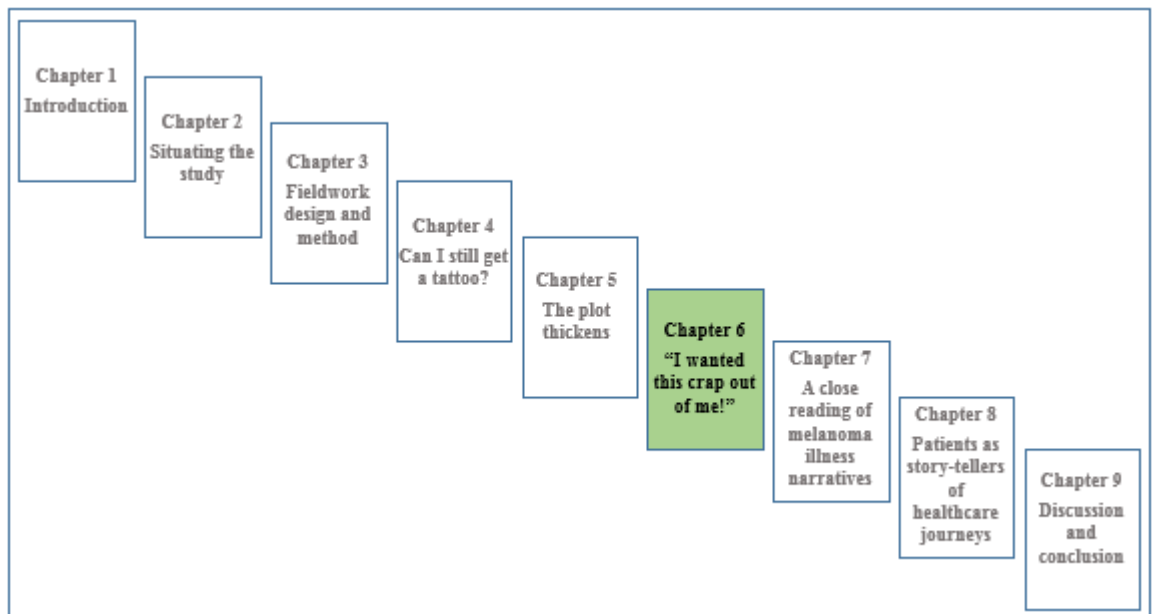
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## 6. “I wanted this crap out of me!”

### A meta-analytic narrative study of web-based personalised texts of 214 melanoma patient journeys in four countries



This chapter investigates the healthcare experiences described in 214 personal accounts of melanoma published on cancer and melanoma support websites. The accounts feature a range of disease stages and reflect medical trajectories spanning across different eras of clinical management in melanoma care. The people who wrote these accounts condensed a complex, dramatic time of their lives—that may or may not have been continuing as they wrote—into a short autobiography. Their accounts are examined to draw thematic conclusions about the experiences that had collective impact at different periods in the patient journey.



## Qualitative Health Research

### **"I wanted this crap out of me!": a meta-analytic narrative study of web-based personalised texts of 214 melanoma patients journeys in four countries**

Journal:	Qualitative Health Research
Manuscript ID	Draft
Manuscript Type:	Research Article
Keywords:	Lived Experience < Health, Health Care, Outcomes < Health
Regions, Cultures, and Peoples:	Australia, Australians, Britain < Western Europe < Europe, Europeans, United States of America < North America, North Americans
Methods:	Meta Narrative < Systematic Reviews < Research Strategies

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**“I wanted this crap out of me!”**

**A meta-analytic narrative study of web-based personalised texts of 214 melanoma patient journeys in four countries**

**Abstract**

Malignant melanoma is an aggressive, recalcitrant disease, and its impact on people can be compounded by the physical and psychosocial consequences of medical management. Providing melanoma patients with patient-centred care that is effective, safe and also supportive throughout their journey from diagnosis to outcome requires knowledge of patients' progressive experiences and evolving perspectives. With ethical approval, we undertook a meta-analytic study of 214 experiential accounts of melanoma collected from the personal story sections of melanoma and cancer support websites. Using a narrative approach, we qualitatively examined the care experiences represented in these accounts, and identified needs for supportive care in a framework reflective of the personal patient journey. We differentiated these across three key periods: the lead-up to diagnosis; diagnosis, treatment and recovery; and post-treatment and recurrence. This paper contributes to the growing body of work that utilises Internet content as sources of qualitative, experiential healthcare data.

**INTRODUCTION**

The rising incidence of melanoma in Western countries (Trakatelli, Siskou et al. 2012, Walter, Birt et al. 2014, Stamatakis, Brunton et al. 2015) is placing new healthcare burdens on patients, and on the services they use (Watts, Cust et al. 2016). As a result of the aggressive, recalcitrant nature of the disease, and also the impact on patients of the complexities of diagnosing and managing the disease, people with melanoma have high needs for supportive care (Barker, Kumar et al. 2011, Molassiotis, Brunton et al. 2014, Tan, Butow et al. 2014, Stamatakis, Brunton et al. 2015). Although we have a great deal of literature on the clinical condition and its medical challenges, and emerging qualitative research is providing insights into the experiences of people with melanoma, the nature of the experiential journey of melanoma patients, from pre-diagnosis through diagnosis, treatment, post-treatment, remission or death, has not been well documented. Thus the interaction between medical aspects of the condition and the social science of the patient trajectory requires our attention.

## **Background**

Melanoma is an aggressive form of cancer with atypical and rare forms that challenge the capacity of people and their physicians to identify symptoms (Abikhair, Mahar et al. 2014, Lin, Mar et al. 2014), so that diagnosis can be an ill-defined, protracted and complex experience (Lipworth, Park et al. 2011).

Conventional treatments of surgery and radiotherapy can result in permanent disfigurement and disability (Noorda, van Kreij et al. 2007, Fogarty, Hong et al. 2014), leaving patients to face enduring healthcare needs, employment issues and relationship concerns (Tan, Butow et al. 2014, Stamataki, Brunton et al. 2015).

Advanced stages of the disease may be difficult to treat, leaving patients with dire choices to make and grievous concerns about their futures (McLoone, Watts et al. 2012, Molassiotis, Brunton et al. 2014). The responsibilities of self-surveillance and management of lifestyle factors associated with the development and recurrence of the disease cause ongoing duress (Oliveria, Shuk et al. 2013).

Further, the involvement of multiple and disparate medical and ancillary care services in melanoma diagnosis and management (Trakatelli, Siskou et al. 2012), and the varying dyadic and organisational policies and practices of healthcare providers (Liberati, Gorli et al. 2015), creates issues for continuity of care.

The disease and its management thus create significant physical, psychosocial and informational support needs that affect large numbers of people with this form of cancer (Loquai, Scheurich et al. 2014, Tan, Butow et al. 2014, Bird, Coleman et al. 2015, Kent, Ambs et al. 2015). With its rising incidence, intensity of personal impact, and ongoing burden on healthcare services, melanoma is conceivably an “emerging chronic disease” (Cornish, Holterhues et al. 2009).

## **Organising principles for research findings**

The patient-centred framing of healthcare obliges clinicians and ancillary healthcare providers to attend to patients’ needs for clinical safety and effectiveness, and also personal support. Though policies and practices of patient-centred care vary across healthcare settings and contexts, there is consensus that care is supportive when it is organisationally and relationally responsive and compassionate towards patients, and empowering (Liberati, Gorli et al. 2015, Gardner 2016). To achieve this goal, healthcare providers need to be aware of the support needs that arise from patients’ “individual susceptibility and adaptation”

(Kasparian 2013) to the disease and its outcomes, and cognizant also of the support needs that arise for patients as a direct result of the progressive events and processes of medical care.

The dynamic, evolving nature of melanoma patients' individual and collective needs for supportive care can be related to impact-critical periods of disease progression and disease management (Tan, Butow et al. 2014, NICE 2015). The small body of research that qualitatively explores the support care needs of people with melanoma predominantly features specific impact-critical periods (see, for example, Oliveria, Shuk et al. 2013, Walter, Birt et al. 2014), in contrast to whole patients' journeys, from diagnosis to survivorship.

Our study set out to fill the gap in experiential, progressive and longitudinal knowledge of melanoma patients' needs for supportive care. We examined progressive 'touch points' and support sensitivities in people with melanoma, drawing on a large, untapped databank of unsolicited, autobiographical accounts of bottom-up experiences of melanoma patients about their condition and its management. The purpose of the study was to identify the experiences and support needs that are significant to people with melanoma *from their perspective*, irrespective of their clinical stage of diagnosis, across the entire journey they undergo, and to synthesise from those findings how, whether and to what extent support needs emerged that may not have been sufficiently identified in prior studies.

## METHODS

**Background:** With its ever-increasing opportunities for self-publishing, the Internet has become a prominent sphere for the publication of illness stories. Creating and disseminating a narrative of one's own experiences of disease and disability offers the writer opportunities for catharsis, facilitates membership of communities of people dealing with the same health condition, communicates warnings and provides advice to others about their own journey and enables personal advocacy of disease and treatment awareness. Illness stories portray the events of illness and of treatment in the context of the storyteller's ordinary life, exposing the "biographical disruption" (Bury 1982) imposed by sickness and disability. Interest from scholars and practitioners in the social and medical sciences and the humanities in these life-framed, autobiographical representations of illness has produced rich insights into the phenomenology of illness and the

personal transformations wrought by illness and treatment (Frank 1997, Charon 2006, Carel 2008, see, for example, Carel 2013:353).

**Rationale:** In this study, the analytic interest in illness stories takes a new approach: autobiographical illness stories are examined specifically for their representations of patients' progressive experiences of medical management and healthcare services: the life-course journey of the person as patient. Illness stories published on the Internet are an emerging, valuable resource for healthcare research (O'Brien and Clark 2010, Mazanderani and Powell 2013), and constitute an under-exploited database of patient-authored, patient journey representations. Advantages of these sources include that they are widely accessible, and are regularly updated by the people undertaking the journey. The narrative structure of the patients' storytelling facilitates the organising of their representations of medical and healthcare experiences into a chronological progression that recreates the specific hurdles they face and overarching journey they travel. The autonomy of the storytellers to decide where to begin and end the story, and how to frame it and what to narrate, firmly grounds the content in their idiosyncratic perspective (Garden 2010, Coulter 2013). The highly personal nature of the content promotes the production of potentially rich and nuanced qualitative data. An added benefit is that *multiple* stories can be aggregated to see what no individual can discern: an overarching meta-narrative.

To mine this rich information seam, we selected a population and harnessed the stories written by people with melanoma, published on websites representing melanoma and cancer support organisations. The focus on melanoma was related both to universality and medicality: melanoma as an illness experience is inherently also a healthcare life-course experience, involving a medically and chronologically framed healthcare trajectory that moves from diagnosis to treatment to outcome, and beyond. Melanoma is a cancer that occurs in both genders, in all ages and in the healthcare domains of all countries.

**Analysing stories of experiences:** Narrative inquirers take an ontological position that story-making makes sense of phenomena (Trahar 2009, Clandinin and Huber 2010, Bamberg 2011) and that the qualitative investigation of human experience can therefore be undertaken through analysis of stories. We adopted this stance. The methods to prosecute that idea have been categorised into three core analytic pathways (Elliott 2005:38): analysis of the *content* of text (Mishler 1995, Riessman 2008)—the experiences recounted in the story and the evaluation

of those experiences by the narrator; analysis of the *form* of the story—the structure and conventions of story creation; and analysis of the characteristics and process of *performance* of the story (Berns 2014). We used this three-point model to guide our analysis.

**Analysis:** The methods employed for our content analysis were framed by an inductive, grounded approach (Thomas 2006, Glaser 2012). The medical and healthcare experiences that constituted the form of the patient journey were derived from the text. Each story was imported into the NVivo software program (version 10.2). A classification sheet was completed for each story that identified the source of the material and the date of publication, where available. It also recorded demographic and health status information that was made explicitly available or that was embedded within the content of the stories. Individual experiences of medical management and healthcare services were identified and then coded with a label descriptive of the germane theme and the chronological circumstance. As an example, in contrast to a meta-category of ‘wait times’, relevant content was coded into ‘wait times for results of initial biopsy’ and ‘wait times for results of subsequent surgical investigation’. In this way, the narrative of progression through medical management and general healthcare services was plotted. This allowed us to derive features of the content, form and performance of individual stories, and facilitate their ultimate aggregation into a meta-narrative.

**Quantitative perspective:** While the primary intent of the study was to produce meaningful qualitative data on autobiographically represented patient journeys, the use of the NVivo coding software made it possible to identify the number of illness stories that featured particular sets and types of experiences. We made simple calculations of these occurrences as appropriate.

#### **Data collection: population and searching procedure**

From June 2015 to February 2016 the Internet was iteratively searched for melanoma stories. Stories were eligible for inclusion if the content represented the illness experience as an autobiographical event narrative. Stories were not eligible for inclusion if they were serialised in a weblog—or ‘blog’—format, on the rationale that these stories were ‘unfinished’. Material that wholly comprised feedback on, or criticism of, a particular institution or clinician was excluded. A full representation of the inclusion and exclusion criteria is provided in **Table 1**.

**Table 1.** Inclusion/exclusion criteria for data collection. The parameters for establishing a ‘story population’ for the study took into consideration content, format and intent of publication.

Included	Excluded
Narrative recounting a personal experience with melanoma	Account of medical trajectory with no descriptive personal framing of the events
Autobiographical	Stories told by third parties
Non-fiction	Fiction or part-fiction
Written	Audio or visual formats
English language	Non-English language
Published on the Internet	Not published on the Internet
Short-story format	Serialised or episodic, books, poems, plays
Self-generated	Interactive
Not written for commercial or proprietorial gain	Marketing content using quotes from patients; positive patient feedback on healthcare services

Eligible stories were primarily identified on the websites of melanoma and cancer support organisations, published in sections of those websites designated for personal accounts of experiences dealing with melanoma. These publication sites were entitled variously ‘survivor stories’, ‘real stories’, ‘real life stories’, ‘personal stories’, ‘patient blogs’ and ‘patient stories’. Stories that appeared to meet the criteria were investigated by an initial rapid read-through, and by a second detailed review when the collection period was over.

## FINDINGS

### Overview

This investigation produced a study population of 214 stories drawn from 17 websites, in four territories: the UK, Australia, the US and New Zealand [see Table 2].

**Table 2.** Population size and territory. The inclusion criteria for English language texts informed the outcome of the territories from which stories were selected. The relative abundance of melanoma illness stories on US websites was managed by a ratio-guided reduction in the number of stories collected from US sites.

Country	No. Sites	All eligible stories	No. Selected	Percentage selected
Australia	5	38	38	100%
New Zealand	1	7	7	100%
United Kingdom	3	11	11	100%
United States	8	227	158	70%
<b>Total</b>	<b>17</b>	<b>283</b>	<b>214</b>	<b>75%</b>

No substantial websites that the searching procedure uncovered were excluded. The publication dates of the stories, from the information available, ranged from 2008 to 2016. The demographic characteristics of the storytellers could not be consistently determined, nor was information about the dates of their illnesses or the clinical stages of their disease readily available [see **Table 3**].

**Table 3.** Scope of study. The scope of the study was grounded in the search for stories that met the criteria for inclusion.

Population size	283 stories identified as meeting the inclusion criteria; 214 selected for data collection.
Territory	Not limited to politically bounded territories, but collected from English language websites.
Demographics	Author's gender was the only consistently available demographic characteristic. Of the 214 stories there were 149 female authors, 64 male authors and one whose gender could not be determined.
Date	Publication dates and dates of illness experiences were not consistently available. From available information, the publication dates ranged from 2008 to 2016.
Health status	Information on the clinical staging of melanoma was inconsistent within and between stories.

The themes identified in the analysis, contextualised by the chronological progression of events, form a representation of patient journeys featuring three impact-critical periods related to support needs: lead-up to diagnosis; diagnosis, treatment and recovery; and post-treatment and recurrence. Within these stages, analysis identified thematically allied sets of represented experiences, within which are subsets of represented experiences. [See **Diagram 1.**]

### **Phase One: Lead-up to diagnosis**

A descriptive exposition of life before the diagnosis of melanoma was included in more than half (n=142, 66%) of the stories analysed in the study. Embedded in these expositions are representations of experiences that characterise supportive needs for information and education in the pre-events of the melanoma patient journey.

#### Patient-led delays (n=41, 19%)

The theme of the represented experiences in this set is the decision by patients to delay seeking medical advice despite the recognition of a potential symptom of illness. Two subsets were identified: delays characterised by psychosocial issues in



relation to own ill health, and delays resulting from lack of, or poor, information about melanoma.

Psychosocial issues: *"They instructed me to get it checked out, but when I finished the course, I put it out of my mind and went back to normal working life. After all, cancer is something that happens to somebody else...isn't it?"* MPNA\_0015A

Issues related to melanoma awareness campaigns: *"Not all malignant melanomas look like the ones you see photos of in clinics and on-line (large/irregular shape/multi coloured). Two of mine looked like ordinary moles..."* MPNA\_004G

### **Clinician and system-led delays (n=72, 34%)**

In this section of findings, people represented experiences of being denied timely access to symptom appraisal, and being denied timely diagnosis due to inaccurate symptom appraisal.

Wait times for specialist appointments: *"I remember feeling anxious about waiting another month to ask about the crusty itchy mole but eventually dismissed my worry and headed back over to the tanning salon for a 'pick me up' glow."* MONA023L

Missed diagnosis: *"The melanoma started as a mole on my back that doctors initially brushed off, two dermatologists checked and said they were ok and then eventually a GP shaved it off (incompletely) at my insistence because the mole had grown so large it was catching on clothing."* MPNA\_022B

### **Conflict over symptom appraisal (n=24, 11%)**

The stories in this group characterise situations in which patients felt their needs for symptom appraisal were not met. They reported engaging in conflict with their clinicians about the diagnostic process, or seeking second opinions.

*"...I pointed this mole out on my arm. He said there is absolutely nothing wrong with it, and that he was not going to take it off. At first I hesitated to say anything else, he was a renowned dermatologist ... 'the Best', but I knew something was wrong, so I spoke up. He again refused to remove it, but once he realized that I wasn't budging he agreed to take it off."* MPNA\_023J

### **Phase Two: Diagnosis, treatment and recovery**

The findings on represented experiences of diagnosis and of treatment are grouped together in this section. In the clinical response to melanoma, the story of diagnosis can also be the story of treatment—a biopsy that removes a mole with significant margins may result in a diagnosis and also double-up as treatment. The

experiences represented in this segment include diagnoses of early stage melanomas that are resolved with a first excision and also later stage melanomas that require wider excision and lymph node removal.

### **News of the diagnosis (n=57, 27%)**

Of the sets of support needs identified, this category was represented in the greatest detail. Four thematic subsets were distinguished: the impact of pre-news events; descriptions and evaluations of the style and tone of news delivery; the contrast between clinicians' reassurances that a biopsy would be okay and the diagnosis that followed; and the emotional impact of the news and its effect on the capacity to hear information.

Pre-news events: *"The oncology department called to make an appointment before I knew the results, which was an unfortunate way to find out it was indeed malignant."* MPNA\_031N

Style of news delivery: *"I knew NOTHING about skin cancer. He chose to tell me a story that day of a former patient of his who he diagnosed with melanoma, and was dead ten years after that from a brain tumour. I've never gone back."* MPNA\_023I

Contrast between reassurance and a subsequent diagnosis: *"I was totally shocked by the results. I hadn't considered that anything like this could happen, and the fact that nobody else had thought there was cause for concern made the results even more shocking."* MPNA\_016A

Emotional impact of news: *"At moments like these, as many melanoma and cancer patients will tell you, you experience a horrible feeling like you're sinking—fathoms below water, with pressure building all over your body. Your eyes are like saucers, your body temperature changes noticeably, and it's like you're in a cone of silence. Your senses are blocking everything out as you become more and more consumed with the possibility of your own mortality."* MPNA\_001C

Impact of news on information processing: *"A lot was said in that meeting but all I remember was, we need to cut it out and make sure it hasn't spread through your body."* MPNA\_008D

### **Coordination of treatment (n=22, 10%)**

This set of representations is characterised by positive descriptions of clinicians meeting patients' needs for coordination of further investigation and treatment. The representations of these events include appointments made for tests, consultations with oncologists and surgeons, and surgery.

*“My GP had already called ahead and made an appointment with a specialist...he had also booked me in for a full CT scan the next day. By my Dr being proactive and having these things booked in advance it took away some of the uncertainty I was feeling and also was one less thing to organise.”* MPNA\_004F

### ***Surgery and recovery (n=62, 29%)***

The representations in this set of experiences relate to wider excision and lymph node testing, and were categorised in four subsets of needs for informational and psychosocial support and information.

Waiting for surgery: *“Surgery scheduled for June 19th! Wtf!? 1 month of waiting—ugh I was angry. I did not want to wait a freaking month. I wanted this crap out of me!”* MONA\_005A

Recovery process: *“I had drips coming out of my arm pit, staples everywhere and was feeling lower than the lowest. I was quite emotional during that week or so and on reflection now I was in rather deep shock.”* MPNA\_001C

Impact of treatment: *“The first time I took a shower and took off the bandages and saw the damage it had caused I cried...a lot.”* MPNA\_05D

Waiting on test results: *“Waiting for the final pathology and staging of the disease was torturous. It took almost 3 weeks for the final analysis.”* MPNA\_025H

### **Phase Three: Post-treatment and recurrence**

In the descriptions of the aftermath of treatment, three key sets of support needs were identified, relating to long-term consequences of treatment, ongoing check-ups and subsequent new diagnoses of melanoma in which the journey begins again.

### ***Long-term physical consequences (n=27, 13%)***

Of the representations of the enduring impact of melanoma treatment, two subsets emerged: representations in which authors describe the consequences as significant and challenging, and representations in which authors evaluate the consequences as tough but tolerable.

Challenging consequences: *“My life has completely changed since my experience with melanoma. I now live with lymphoedema and the pain and discomfort associated with that.”* MPNA\_027F

Tolerable consequences: *“Am overjoyed to have my life back, however the permanent side effects have been rough. Severe peripheral neuropathy and damage*

to my heart (pacemaker and heart failure medication). All-in-all I would do it all again.” MPNA\_032F

### **Ongoing check-ups (n=22, 10%)**

Representations of regular reviews following melanoma treatment are characterised by needs related to lifelong dependence on medical management for evidence that the cancer has not recurred or metastasised and also to assuage anxiety about recurrence and metastases.

*“I had three month check ups for 2 years, then six monthly for 6 years then yearly check up ever since. I will continue to go every year and I can tell you every time I go I’ll still feel sick to the stomach due to the past but as soon as Dr [X] says, it’s all looking great see you in a year that’s all that matters.”* MPNA\_008D

### **Recurrence and metastases: the journey begins again (n=47, 22%)**

In the findings on represented experiences of recurrence of melanoma, support needs differed particularly in relation to the diagnosis of metastasised melanoma. Symptoms were less often skin-related and more often related to lumps, pain, headaches, mobility issues and organ function impairment.

Just fatty tissue: *“I was almost 2 yrs cancer free when I noticed a bump just above my elbow not too far from my primary. I went in for a check with my primary doctor and asked him to look. He removed my first melanoma. He said it was most likely a fatty tissue and would remove it for peace of mind—great, one less thing. I then get the call to call him back ASAP. I knew. The dreaded M word.”* MPNA\_05V

## **DISCUSSION**

This study of 214 autobiographical illness stories identifies, describes and enables the categorisation of the progressive events and processes of medical management and associated needs for support experienced by people with melanoma. This study constitutes the first qualitative representation of the expressed stories *en masse* and the support needs in the melanoma journey, drawn from melanoma patients’ own accounts of their experiences and framed by the phases of melanoma management as perceived by patients. In the discussion that follows, we identify where particular themes and topics identified in this qualitative study are underpinned by findings of other qualitative or quantitative studies, and where the findings of our study highlight novel perspectives or identify new opportunities for the investigation of support needs.

### The global overview of support needs

The examination of the needs of people with melanoma, in a framework that is reflective of the personal patient journey, identified needs from an experiential, progressive and longitudinal perspective. The three impact-critical periods for support that were distinguished included a period of lead-up to diagnosis that was characterised by different needs for support than those represented at diagnosis. Diagnosis was identified as a turning point in support requirements, after which the range of needs related to heightened emotion, information-management, the impact of treatment and issues related to recovery. The lead-up to diagnosis as a discrete impact-critical period in the melanoma journey became visible because of the narrative representations of melanoma experience in the data; conventionally, illness storytelling begins with an exposition of life prior to the point in which ordinary life is changed by diagnosis (Lamprell and Braithwaite 2016).

### Phase One: The lead-up to diagnosis

In the complex, diverse path to diagnosis identified in this study, the action—and inaction—of both patients and clinicians had the propensity to, and often in fact caused, delayed diagnosis of malignant melanoma. Patient-led delays in seeking advice on symptoms of melanoma have been quantified elsewhere (Carli, De Giorgi et al. 2004, Tyler, Rivers et al. 2005, Hajdarevic, Hörnsten et al. 2014). However, few studies have investigated patient-reported needs for support in melanoma symptom appraisal. The findings of our study are underpinned by the findings of Walter et al, arguing that there is a need for more relevant images in melanoma awareness campaigns and greater community education on the imperative of seeking symptom appraisal (Walter, Humphrys et al. 2010).

A key experiential issue requiring supportive management related to wait times for specialist appointments. The dissonance between melanoma awareness campaigns promoting urgent attention to symptoms, and wait times for specialist symptom appraisal, caused substantial distress. While the personal impact of wait times is under-investigated, time-to-appointment periods have been reported elsewhere (Lipworth, Park et al. 2011, Murchie, Campbell et al. 2012, Hajdarevic, Hörnsten et al. 2014). We identified wait times of six weeks to four months, which is at the benchmark of other research (see, for example, Lipworth, Park et al. 2011, Cheng, Moreau et al. 2014).

Another significant area of supportive needs identified in the period leading up to diagnosis relates to the impact of misdiagnosis and lack of person-centric responses to patients' requests for symptom appraisal. Just over a quarter of the personal accounts in our study described experiences of a missed clinical diagnosis, reflecting the quantitative evidence from Blum et al reporting between 20 and 33 per cent of clinicians in first consultations giving a misdiagnosis (Blum, Ingvar et al. 2007), and findings of Lipczak et al (Lipczak, Dørflinger et al. 2015) that up to 25 per cent of reviewed cancer patients experienced diagnostic errors. The narrative representations of these experiences in this study display a duality of patient expectations of the diagnostic process. Most patients expressed a reliance on a high accuracy rate from general practitioners and dermatologists, and willingness to accept the symptom appraisal they had been given. However, some 10 per cent of our personal accounts described conflict with physicians about unmet needs in the symptom appraisal process.

#### Phase Two: Diagnosis, treatment and recovery

Our study highlights that news of diagnosis is a turning point in the lives of these patients, triggering significant psychosocial concerns across the diagnostic-through-recovery period (Al-Shakhli, Harcourt et al. 2006). This progressive phase is characterised initially by needs related to the immediate impact of the news of the diagnosis. The delivery of that news, which has been poorly investigated from the patient perspective (Schofield, Butow et al. 2003), had a far greater resonance for our population than is reflected in other studies on patient support needs in this period of melanoma management. Choudhry et al studied preferences for communication of diagnosis and concluded that patients should be asked their preference at the time of initial consultation (Choudhry, Hong et al. 2015).

In some of our patients' stories, the personal impact of the news was shaped by pre-news events such as phone calls from doctors' offices asking patients to come see the doctor earlier than existing appointments, seeing the word 'melanoma' on the file while in the waiting room, or the reassurances that there was nothing to worry about—a phrase that was commonly used—prior to receiving a diagnosis. The capacity of patients to absorb news of a diagnosis also featured prominently. The heightened psycho-socio aspects of the diagnostic situation have been acknowledged elsewhere (see, for example, Horner, Ludman et al. 2013, Seifart, Hofmann et al. 2014). Our study, however, provides qualitative texture to how

people can suffer shock and bewilderment at the time the news of a melanoma diagnosis is communicated.

In this phase of melanoma management, wait times for surgery and for test results were characterised as periods of anxiety, fear, frustration or confusion, or a mix of these. While quantitative reports have been published of obstacles in the pathway from diagnosis to treatment (Trakatelli, Siskou et al. 2012), including the surgical interval after initial excision (Boland, Prichard et al. 2015, Lott, Narayan et al. 2015), the need for support during wait times for melanoma surgery is clear, particularly given our informants often note that the experience of waiting patiently for surgery conflicted with clinical advice that indicated that melanoma is an aggressive cancer.

Textual extracts featured in our results included rich descriptions of the challenges of the recovery period, with representations of shock about the size and impact of the surgical excisions, and the consequences of lymph removal. Lack of preparation for these outcomes, identified in other research (see, for example, Tan, Butow et al. 2014, Stamataki, Brunton et al. 2015) points to a need for improved information provision prior to treatment, and significant physical and psychosocial support in recovery and follow-up. Our analysis also identified support needs relevant to decision-making about further treatment options, the likely effects of chemical therapies, preparation for clinical trials, and psychosocial adjustments to treatment 'successes' and 'failures'.

### Phase Three: Post-treatment and recurrence

Our study identified that the experience of melanoma, regardless of the stage of the disease, has longitudinal physical and psychosocial impacts. A dominant theme immediately post-treatment through to the longer term was the perennial threat of recurrence of the disease hanging over people. Ongoing follow-up appointments were viewed with fear, trepidation and anxiety, related to a potential diagnosis of recurrence, and yet were also positively anticipated for the possibility of medical and psychosocial reassurance. In our study, patients expressed an expectation that clinicians would respond to patients' psychosocial issues such as fear of recurrence during follow-up consultations. The issue of the role of follow-up consultations is an emerging arena of research (see Mitchell, Callaghan, Street, Neuhaus, & Bessen, 2014; Rychetnik et al. 2012; Wevers et al. 2014). Ongoing follow-up appointments were also perceived as sources of information on self-surveillance and sun-related lifestyle management, reflecting the complex expectations affecting patients'

longer term interactions with healthcare services (McLoone, Watts et al. 2012, Rychetnik, McCaffery et al. 2013, Tan, Butow et al. 2014, Bird, Coleman et al. 2015). The medium-term impact of investigative and therapeutic melanoma surgery and chemical treatments represented in the data also underpins the need for attention to the role of ongoing support care. Descriptions of the impact of ‘collateral damage’ of melanoma treatment included embarrassment, distress, self-blame and practical burdens related to scarring, lymph impairment, decreased sensitivity, mobility and functionality. Needs for informational, psychosocial and practical support underscored patients’ expectations of lifelong utilisation of medical and healthcare services.

The final set of experiences in our patients’ renderings of their condition featured the actual return of the disease. Our framework of findings reporting subjective experiences in impact-critical periods suggest that a cycle of support needs is repeated in recurrence of melanoma, with a diagnosis experientially pushing patients back to the beginning of their journey. Significant differences between support needs in a first and subsequent diagnosis of melanoma were found if the diagnosis was metastasised melanoma. In particular, differences in symptoms drove different diagnostic pathways with fewer obstacles to clinical symptom appraisal. Broadly, however, the categories of support needs in each impact-critical period were consistent across first and subsequent diagnoses, regardless of the progression of the disease, with acknowledgement that the nature and timing of needs for supportive care were personal and individual. This is the first study we are aware of that has reported on the support needs of people with melanoma in the context of first and subsequent diagnoses.

## CONCLUSIONS

This study aggregated and synthesised publically available texts representing the experiences of people managing melanoma, identifying the progressive healthcare experiences and support needs that define the melanoma patient journey from the patients’ points of view. Through a critical inquiry into the medical and healthcare narratives embedded within melanoma illness stories, the study arrives at a global, template view of a patient journey as a series of healthcare-related events on the continuum of life experiences that characterise illness. Conceptually, the paper fills in details of the melanoma patient meta-journey as a phenomenon whose distinct, progressive trajectory can be identified in individual autobiographical melanoma illness stories.



Our research also makes a contribution to the emerging healthcare research paradigm in which the investigation of phenomena is enabled through the collection of raw online data available for public inspection. Using a multi-disciplinary approach that integrated the principles of narrative inquiry, grounded methods and narratological frameworks for understanding autobiographical stories, the study created a blueprint and methodological model for tapping into the rich source of data in patient experience research available in unsolicited personal accounts of illness published on the Internet (O'Brien and Clark 2010, Mazanderani and Powell 2013).

#### Strengths and weaknesses

The narrators of the melanoma stories selected for the study are a skewed population: people who express themselves through writing, who use the Internet as a medium of communication, and who are members of communities in which writing about personal experiences of an illness is possible or even commonplace. Demographic information of unsolicited stories published on the Internet can be fragmented and incomplete. Working with unsolicited stories prevents standardisation in the subject matter and narrative structure, and constrains the consistency of data: some people included details of the pre-diagnostic and diagnostic periods, while others simply noted that they had been diagnosed with melanoma and then shifted focus to the treatment and recovery process. However, countering these limitations is the richness of the data set and the authenticity of the participants' accounts. The study has been able to draw from these narratives insights into specific critical events that underpin needs for supportive care, and create a template meta-narrative representation of the life experiences of melanoma patients.

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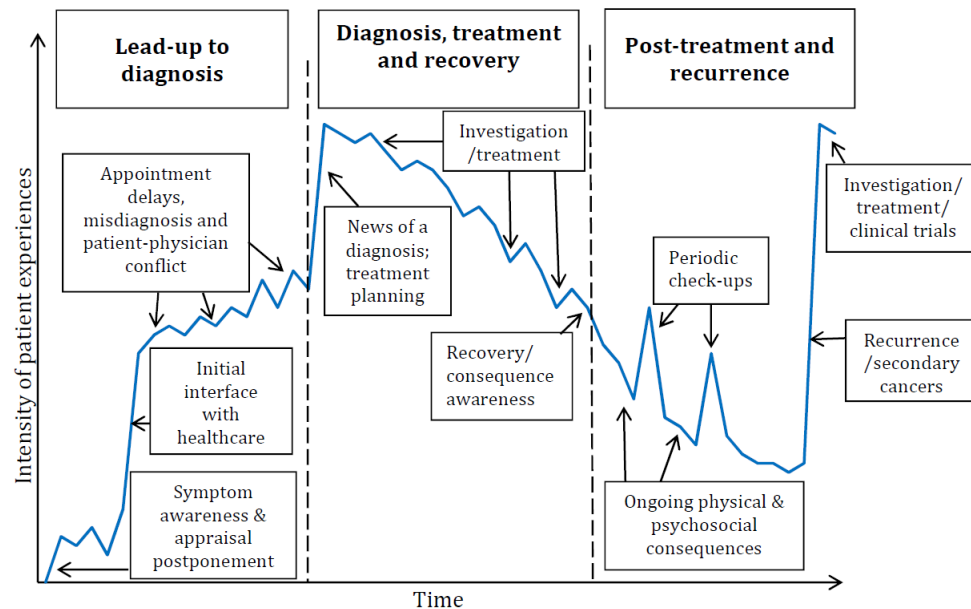
#### **Ethical considerations**

Approval for the study was for the study was obtained from Macquarie University Human Research Ethics Committee (Humanities-Executive).

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**Diagram 1:** Visual representation of aggregated patient journey. Our analysis of 214 illness stories written by people with melanoma identified the journeys that people take, and the progressive needs from healthcare services that are implicated in that journey, in three broad stages: a first phase, which comprises the events in the lead-up to diagnosis; a second phase, which comprises the delivery of the news of diagnosis, planning for further investigation and treatment, treatment and recovery; and a third phase, which is enduring and lifelong. The experiences and needs within each phase may be, and often are, recurring and iterative.



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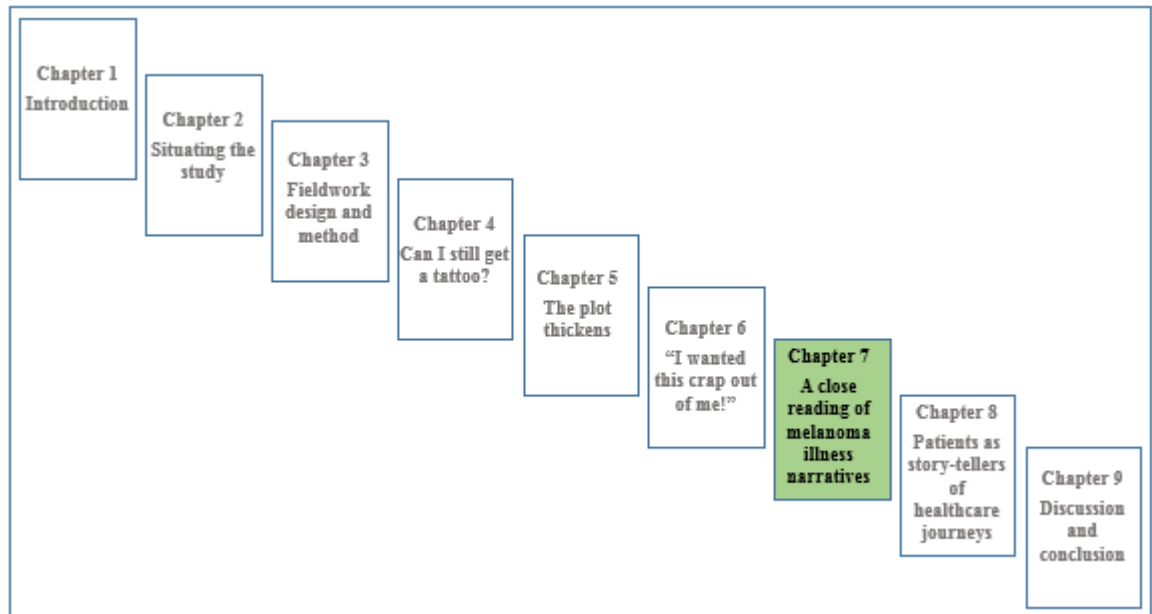
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## 7. A close reading of melanoma illness narratives



The writer Leo Tolstoy is credited with saying that only one of two things ever happens in a story: a person goes on a journey or a stranger comes to town. Metaphorically, in melanoma, both things happen—a patient goes on a journey because a stranger has come to town. In this chapter I explore the ways in which extant plots and literary devices are used by the authors of illness narratives. By analysing these narrative heuristics it is possible to see the perspective-framing ways in which people highlight the healthcare experiences that are meaningful for them and how they construct patient-centric, longitudinal views of the melanoma journey.

## Medical Humanities

### A close reading of melanoma illness narratives

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## A close reading of melanoma illness narratives

### Abstract

Autobiographical patient stories offer researchers rich sources of potentially surprising knowledge about being a consumer of healthcare services, about the personal relevance and safety of medical management, of the phenomenology of illness and patienthood, and of the impact of illness and medical care on identity. Knowledge of how patients perceive and convey their whole-journey experiences is critical in designing, sustaining and facilitating feedback on patient-centric healthcare systems. However there is as yet little in the way of theoretically founded, systematic collection and analysis of patient stories, particularly with regard to patient stories published digitally. This study makes a contribution by exploring 214 unsolicited, web-published personal accounts of a melanoma patient journey. The stories were collected from 17 websites based in four countries: the United Kingdom, Australia, New Zealand and the United States of America. The study seeks to understand not only *what* is conveyed in the content of stories told by people who have been diagnosed with and treated for malignant melanoma, but *how* these people 'story' their lives to create a cohesive, culturally acceptable portrayal of what may have been, or still may be, a complex, disorderly, and fragmenting set of experiences. The study thus pays attention to the events of the story, the form of the narrative, and the act of narration.

### INTRODUCTION

Illness stories, most commonly referred to as 'illness narratives' and sometimes 'pathographies' (Hawkins 1999), have become the subject of specialized inquiry in the new analytic arenas focused on interconnections between illness, health, medicine and the humanities. Conceptually, an illness narrative is a story about a person's transition from good health, to poor health and then to some kind of outcome—which may be a situation of resumed good health, a different level of health requiring ongoing management, or even death—and which expresses the impact of illness on a person's life (O'Brien and Clark 2012). This concept of illness narratives is trans-genre, and trans-discipline; it takes into account the narratological, bio-psychosocial and medical elements of the stories people tell about illness, and appreciates that such narratives occur in social, clinical, research and arts settings. The language used to report on a study of illness narratives intermittently draws from the terminology of medicine, humanities and the

psychosocial sciences.

In this paper we explore the written illness narratives of people with melanoma. The incidence of melanoma is rising throughout the Western world (Stamatakis, Brunton et al. 2015). People with melanoma face aesthetic outcomes of biopsies and surgeries (Buck, Rawlani et al. 2012, Lee, Klassen et al. 2016), the functional and psychosocial consequences of side effects, especially from lymph removal (Oliveria, Shuk et al. 2013, Cromwell, Chiang et al. 2015) and a poor prognosis for those in advanced stages of the disease. Ongoing surveillance is necessary because melanoma has a high 'rate of return' and can metastasise many years after a primary melanoma has been removed. People with melanoma thus live with a fear of recurrence (Kasparian, Mireskandari et al. 2016), a lifelong dependence on healthcare services and a concern for lifestyle choices that expose them to the sun (Palesh, Aldridge-Gerry et al. 2014). Melanoma is a complex, unruly disease.

While great advances are being made in chemical treatments, particularly in relation to targeted, personalized therapies, the healthcare trajectory of a person with melanoma constitutes a dramatic narrative with logistical and psychosocial implications for patients and organizational and economic implications for healthcare systems. Knowledge of patient experience in this arena is crucial. However, the healthcare experiences of people with melanoma are under-examined from the patient point of view (Barker, Kumar et al. 2011). The illness narratives of people with melanoma present an opportunity for researchers to expose the world of people with the disease, from their perspective.

A diagnosis of melanoma reframes a remembered past of childhood days in the sun. It destabilises the present by interrupting social and work-related plans. And it corrupts well-imagined futures. For people with melanoma, the Internet offers prospects for autobiographical description and expression of all that has happened, is happening and might happen to them. In addition to the websites set up by individuals who want to support others with melanoma, the websites of organisations that champion research into the disease provide portals into supportive melanoma communities and publishing opportunities for people who want to tell their stories. After securing ethical approval from Macquarie University Human Research Ethics Committee, we turned to these websites to establish a population for our study.

## BACKGROUND AND AIMS

Seeking data from unsolicited stories is a growing means of inquiry into patient experiences (O'Brien and Clark 2010, Greaves, Ramirez-Cano et al. 2013). In addition to the melanoma-focused websites we accessed, there are sites that facilitate patients to tell stories of healthcare experiences, there is the 'blogosphere' of the Internet, and there is social media. These digital opportunities to tell the story of oneself are different to the illness narratives published in books most especially in their relationship with an audience. Implicit in the telling of every written story is a listening, or reading, audience. In digital forms of storytelling the audience is semi-targeted and therefore largely known, and also 'close'—more immediately and potentially interactive than the audience for a book.

This tailoring of illness narratives to the perceived needs and interests of an implicit audience can make it difficult for researchers to collect data that serve their interests and goals. Whereas in interviews the researcher can set the stage, focus attention on a theme, and then interrupt a participant to expand a description or extend a thought, the researcher working with illness narratives has a ready-made text to investigate. In interviews and discussion, a researcher can influence storytelling tone by interacting in ways that appease or irritate the participant, whereas in illness narratives the tone is set. Further, written illness narratives organise the representation of experiences into a narrative structure elected by the storyteller; in interview the researcher can influence or even distort narrative structures by moving participants into arenas of experience they might not have opted to represent, and are not confident to express.

The research text and the unsolicited text are thus differentiated by the comparative autonomy of the storyteller and comparative sovereignty of the researcher. This is resonant with the difference between top-down and bottom-up research, or emic verses etic approaches. While patient stories are widely heralded in patient-centric healthcare environments as a 'way in' to understanding patient experience, there is yet little in the way of theoretically founded, systematic collection and analysis of illness narratives. Issues of autonomy in authorship and the power of the researcher to manage and manipulate data when dealing with written personal accounts of illness and patienthood have not yet been conceptually addressed. Indeed there is some eschewing of the use of illness

narratives as sources of data. This is primarily related to the potential for research to deconstruct the narrative of the story into experience as evidence, and to thereby diminish the story as a deep expression of suffering and transformation. This paper aims first, to dissuade the disbelievers and encourage the researchers who would access these richly experiential texts as sources of data. Our goal, second, is to establish a narratological analytic framework that attunes researchers to the very personal nature of the experiences represented by storytellers and also provides access to the ‘evidence’ contained in the story. The approach we take is to identify the way in which narrative conventions personalise content and convey meaning in the written illness narratives of people with melanoma. This premise—that “a text’s meaning is carried in the dynamic relationship between what it is about and how it is built” (Charon 2006:362)—informs our methodology.

## METHODOLOGY AND METHODS

### **Approach and scope**

‘Narrative’ can be understood as a cognitive process and also the representation—the reported output—of that cognitive process. ‘A narrative’ can be understood as a set of experiences which are represented as occurring in response to an event and a goal, which are boundaried by a beginning and endpoint, which are given meaning through description and reflection, and which employ in their construction the archetypal storytelling conventions and socio-political narratives of the storyteller’s communities and cultures. Narrative inquiry is a mode by which a researcher enters an experience or investigates a phenomenon, either by facilitating people to story their experience or by examining an experience that is already storied, the latter being the intent of this study.

Researchers seeking knowledge of patients’ experiences can look to the biomedical, phenomenological or psychosocial content of illness stories for insights into the experiences of people with melanoma when they become patients. They can learn also about the experiences of patients as storytellers by taking into account the processes that have informed the construction of their illness narratives. The scope then is that the analysis of the written illness narrative “... goes beyond the text itself and asks questions about the narrator and the act of narrating” (Greenhalgh 2013).

Narratology is a multi-disciplinary arena that identifies “the logic, principles, and practices of narrative representation” (Meister 2014). Narratology points to the

cognitive and representative processes of narrative and also to the ways in which those processes reflect the narrative customs and routines of the particular communities people engage with and through the popular stories and entrenched narratives of wider culture. “The ill body’s articulation in stories is a personal task, but the stories told by the ill are also *social* ... From their families and friends, from the popular culture that surrounds them, and from the stories of other ill people, storytellers have learned the formal structures of narrative, conventional metaphors and imagery, and standards of what is and what is not appropriate to tell” (Frank 1997) The agreed processes of story creation enable the ‘tellers’ of melanoma illness narratives to organize their biographical experiences and to share their lived experiences with others—beyond the representation of facts and into the realm of personal meaning.

What narratology does for this study is offer a stable of analytic reference points by which to investigate the illness narratives that make up the ‘population’ of the study. The analytic framework then can be conceived as top-down. However it is also a grounded study in that it seeks to produce a theory of narrative analysis of illness stories, from the evaluation of the data. Grounded theory advocates for research methods that allow findings and explanatory theories to ‘emerge’ from the raw data, achieving analytic outcomes that are inductive (Thomas 2006) in contrast to approaching the raw data with preconceptions. The study can be considered, then, a grounded narrative inquiry into illness stories, framed by the principles of narratology.

### **Data collection**

We sought written, autobiographical texts that chronicled the events of medical and ancillary healthcare from the perspective of a person with the disease and conveyed the personal impact of those experiences (Garden 2010, O’Brien and Clark 2010). The criteria for inclusion are laid out in Table 1.

**Table 1:** Criteria for inclusion of unsolicited web-based narratives in the study.

<b>Included:</b>
Narrative recounting a personal experience with melanoma
Autobiographical
Non-fiction
Written

English language
Published on the Internet
Short-story format
Self-generated
Not written for commercial or proprietary gain

Unsurprisingly, searching the Internet using the terms ‘melanoma illness narratives’, or ‘melanoma narratives’, yielded mostly scholarly papers. Using obvious synonyms, such as ‘story’ and ‘account’, yielded a wealth of material, however the content was not necessarily narrative, or autobiographical, or published in written form. Instead the yield included marketing material featuring patient feedback on healthcare institutions, factual information on melanoma, video and audio compilations of interviews, accounts written by the families and friends of melanoma patients, and contributions to forums. Testing search terms such as ‘personal’ and ‘experience’ yielded more refined results, with a selection comprising 286 short-form autobiographies of melanoma experiences posted to cancer support websites. The final population of 214 melanoma stories met the criteria

### **Data familiarization**

Before analysis, each story was read multiple times. The stories were read at least once, briefly, in the first instance as part of the population selection process, again in the pre-selection process, and again at least once to confirm final selection. The demographic information on each storyteller was inconsistent between websites, so that it was not always possible to read a story with a sense of whether the storyteller was male or female, what age group he or she belonged to, and where he or she lived. Because of publication on the Internet, people living in one country were able to publish on the websites of organizations based in other countries, so geographic information was not always available. Some stories were published with names while others were not, and it was not possible to know if the names used were nom de plumes. It was not always possible to know, either, much detail about the diagnosis. The extent of melanoma is referred to as ‘staging’, the details of which are explained in the appendix. Some websites categorized their stories according to the staging of the disease, so stories were published, for example,

under Stage I, Stage II etc. Others published all stories together in order of date of publication with no differentiation related to staging.

Overall, then, what we learned of the narrators of these stories came to us largely from the little that was made explicit, and deduction. We were led by mentions of a gender-related experience, or descriptions of conversations with physicians that hinted at the staging of the disease, or mentions of family that hinted at the ages of the storyteller. By the time we came to analysis we knew each of the stories well, and by engagement with the content, had a sense of a relationship with the narrators.

## **Analysis**

We entered each story into NVivo software, and used the coding and memo tools facilitated by the program to organize the stories as data. We then conducted an iterative analysis using a framework based on the “central features of narrative” (Charon 2006:40) which comprise character and narrator, plot and time, and also taking into account the influence of the narrative models that characterise a culture (Bruner 1988/2004:694). Table 2 provides details of the analytic framework.

**Table 2.** An analytic framework for comprehending meaning in the construction of written illness narratives.

<p><b>Character:</b> The authors of autobiographies have three functions: creator, narrator and protagonist. Though an audience is led to believe that a narrator is the central character because of the convention of using the first person in the telling of an autobiographical story, narratologically they are not the same: the narrator is a character who represents the author’s self. The degree to which this “homodiegetic” (Genette and Lewin 1983:51) narrator creates an identifiable, relatable, self-as-protagonist (Margolin 2013) depends on the choices made by the author about the narrator’s style of representation—his or her ‘voice’. In autobiographical representation, characters other than self are narrated by the use of the third person.</p>
<p><b>Plot structure and plotlines:</b> Authors choose events, consequences and responses for representation and then plot them to represent them as inter-related events (DiYanni 2000). A plot of a story is characterized by a conventional structure of beginning, middle and end, and by the progressive sequencing of events along that structure (Kukkonen 2014). Through the plot structure and plotlines that run through the story, events are given meaning.</p>
<p><b>Normative socio-cultural narratives:</b> The ways in which humans story experiences and the kinds of events and characters we choose to represent are informed by the dominant lived and imagined stories of our societies and cultures. Collectively these stories embed normative narrative processes and also normative</p>

characterisations of self and others that are reflected in the stories people tell.

**Time and space in the unfurling story:** Stories are shaped by temporal manipulation of past, present and future. There is the “time traveled in the course of the narrative’s plot” (Charon 2006:120), the location in history of the events that are represented, there is also the temporality of the story-teller’s identity as narrator and protagonist: the author’s self in a particular time and space (Bamberg 2012).

## FINDINGS

We present our analysis of the 214 unsolicited texts that made up our study population under the structure of the four-fold narrative framework provided above.

### Character

The use of first person, which facilitates the duality of ‘self’ that is narrating the story to a perceived audience, and ‘self’ that is being narrated (Schwalm 2014), was an identifiable convention in all but one of the population of 214 stories we investigated.

*“All it took was one freckle she happened to spot on her back - the size of a tip of a pencil. It doubled in size, then tripled.”—*

MPNA\_003B

Secondary characters: The characters who played secondary roles in the stories included physicians and other healthcare professionals, and friends and family, other patients and hairdressers who noticed symptoms. Illness also featured as a character in the form of an antagonistic entity:

*“I live my life with this ever-present invisible stranger with nothing but bad intentions.”* MPNA\_014B

*My life changed forever when an unwelcome intruder came knocking at my door.”* MPNA\_014A

*“I lost most of my nose to the BEAST.”* MPNA\_005U

Narrator: We identified four kinds of protagonist/narrators: reportive, descriptive, reflective and supportive (see Table 3). The descriptive narrator allowed a level of intimacy with the perceived audience by way of the level of detail. The reportive narrator described facts, and in particular employed language is reflective of biomedical terminology. The reflective narrator was often a literary communicator, employing depth of detail and extensive metaphor. The reflective narrator commented on own response to events and also rationalised feelings with



intellectual positioning, representing an ‘inner’ monologue. This was the voice of an existentialist, representing events as meaning-making, or the voice of someone in pain and chaos. The supportive narrator was focused on bringing knowledge gained from his or her own experiences to the perceived audience. Reflective and supportive narratorship was particularly evident in the prologues and epilogues to the stories.

**Table 3:** A typology of narrators. The four overarching styles of narrator are categorised here with examples of the styles.

Type of narrator		Example
<b>Reportive</b>	Factual	<i>“I started with a black spot on my left shoulder that starting bleeding. On December 31 (new years eve) 2008 the dermatologist called to tell me it was melanoma. Since that time, 2008 to 2013, I have had four surgeries and was told in June 2014 that I was stage 4.”—MPNA_032I.</i>
	Medical	<i>“Before I was diagnosed with Metastatic Melanoma I, I was diagnosed with CLL stage 1 in Dec, 2000. No apparent symptoms except a high consistent high wbc &gt;60k. I have been taking IVIG infusions to build up my immune system on a monthly basis for the infections from the CLL.”—MPNA_31C</i>
<b>Descriptive</b>	Metaphoric	<i>“Tonight was my 7th slice and dice in the past 6 weeks and to use my surgeon’s words ‘it was epic’.” — MPNA_031F</i>
	Animated	<i>“It seems that every second or third person has a cancer story. A journey, a lot of people call it, and I suppose in a way it is. But my cynical side says “Really!!??” A journey for me would be a little more fun with a dash of adventure.” —MPNA_032B</i>
	Dialogic	<i>“I noticed that she [the doctor?] had some difficulty looking at me, and I made it easier for her. I said, “there isn’t anything new out there for me, is there?” She said, “no,” and we just sat there for awhile.”— MPNA_035A.</i>
<b>Reflective</b>	Introspective	<i>“I had the surgery, Wide Local Excision and was surprised by the amount of tissue they removed. Morbidly enough I took a picture of the specimen and stitches before they packed me up. They cut down to the muscle.” MPNA_029N</i>
	Appreciative	<i>“I have been blessed with the incredible support of family and friends. It is these wonderful people who stand by you the tough times and celebrate with you the good times.” — MPNA_001B</i>
	Rationalising	<i>“Sleeping at night is hard too between the anxiety and my leg falling asleep no matter what position I’m in. But ohhh well, I always think it could be worse.”— MPNA_005K</i>

	Transformative	<i>"I WILL get through this. I spent so much time crying and feeling sorry for myself that now I just get angry and determined to get healthy, get rid of this, and live the life my family and I deserve." MPNA0029J</i>
Instructive	Supportive	<i>"Take the days and nights given, strive to love and appreciate it for what it is worth." —MPNA_001A</i>
	Activist	<i>"Tanning is never safe even if only doing for a short time for something like the prom". MPNA023F</i>

### **Plot structure and plotlines**

All but two of the stories employed some or all of the structural conventions of oral and literary storytelling. We categorise these conventions and their use in the stories in Table 4.

These conventions included:

**A prologue comprising** text that is situated before the emplotted story begins, summarising what is about to be recounted or introducing the narrator to the audience:

*"My story has had many up's and downs and many twists and turns but...I would like to share my story in the hope that it will help others." MPNA\_001C*

**An expositional set-up** to the story that tells the audience what 'ordinary' life was before diagnosis, either in a causal relationship with the diagnosis of melanoma that was to come, or by means of contrasting the order of ordinary life with the chaos of the disease:

*"I grew up on a dairy farm.... I rarely used sunscreen. I would go out in the field in a tank top and shorts. I had numerous sunburns. I remember having trouble sleeping some nights due to painful sunburns." MPNA\_005R*

**A 'turning point'** of an inciting incident that propels the main character into action. In these illness stories this inciting incident was most often the discovery of a new mole or a change in a mole, or in the case of metastases a lump:

*"My girlfriend told me the mole on my back...was bleeding. I figured I had scratched it on something. She told me I should go see a dermatologist. So I did, but not because I was worried or anything, I just figured it would shut her up." MPNA\_0030A*

**‘Rising’ action leading towards a climax** or period of greatest tension, characterised by the period of diagnosis, treatment and short-term recovery:

*“The lymph node removal was even worse than the 5-inch scar that was left. So very sore. The 2 weeks my family and I waited to get the results on the lymph node biopsy was more stress than you can imagine.”* MPNA\_029G

**‘Falling’ action and resolution**, characterised by long-term recovery, clinical follow-ups and surveillance checkups:

*“Although this drug has saved my life I am not clear of the disease. But my progression free survival has reached 18 months with no sign of abating.”*  
MPNA\_008B

**Repeat structure:** In the cases of recurrence or metastases, the prologue and epilogue were bookends to a repeated plot structure.

*“Then, in mid-July, I felt a lump underneath my left ear, an inch or two from where the melanoma was removed. I told myself it must be a cyst. I had had a half dozen of those removed over the years. Yeah, that must be it. However, I knew better. I just couldn’t say it out loud.”* MPNA\_025B

**An epilogue**—text that is situated at the end of the emplotted story, summarizing what has been recounted or framing the experience for the audience:

*“Life really is short, it should be treasured on a daily basis. Will it be a truck, cancer, old age, armed robbery, collapsed mine? No-one knows it really is out of our control. Take the days and nights given, strive to love and appreciate it for what it is worth.”* MPNA\_001A

**Table 4:** The structural conventions of written storytelling that feature in illness stories, and the extent of their usage.

Structural conventions	Percentage of stories
Prologue	43% (n=92)
Set-up	50% (n=106)
Inciting incident	80% (n=172)
Rising action and climax	100% (n=214)
Falling action and resolution	97% (n=208)
Repeat elements of structure	23% (n=50)
Epilogue	78% (n=167)

## **Plotlines**

We identified two common kinds of plots in these illness narratives: a biomedical plot and a personal, self-identity plot.

Biomedical plots: The biomedical plot sequenced events that included the discovery of a symptom, clinical consultations, diagnosis, decisions made about treatment, treatment, recovery and post-recovery life. All storytellers organised their stories around a biomedical plot; some included only a few of these events, others chose one of these events to plot out in detail and some ‘collapsed’ the plot:

*“ I was diagnosed in March 2015 with Stage III melanoma on my left arm, after I noticed a mole that was itching and changing. The mole was removed with a large excision and one of five lymph nodes came back positive for melanoma. I had a complete left groin lymph node dissection in August. I was advised to wear stockings on my arm for six months. I just stopped wearing them a few weeks ago. Didn't know if they helped then, but now I know they did. I just start wearing them again because it just works better for me for now - no or little swelling. I still have a hard time with exercise.” — MPNA\_005K*

The complexity or simplicity of biomedical plots was a product of the choices made by storytellers about what events to include, but was also determined by the nature of the melanoma experience. The plotlines of storytellers in advanced stages of the disease were complex and involved numerous twists and turns including misdiagnoses, post-surgery lymphedema, recurrences and metastases. The plotlines of storytellers with early stage melanoma were more straightforward: the cancer was diagnosed early, removed quickly, involved no spread to the lymph glands, and there was little talk of recurrence or metastasis.

Personal, self-identity plots: All the stories comprised representations of the personal meanings associated with the events of biomedical plots, because this was a criteria for inclusion in the study. Some narrators noted how certain events made them feel. Others represented their responses as sequenced, progressive and transformational, using literary prose:

*“My mortality lay down on me like a heavy, itchy, woollen blanket. Every night, it was my loyal companion. Most friends fell away, but the real ones stuck around. My new friends keeping me company were fever, vomiting, and diarrhea. Miraculously, they brought wisdom, insight, and compassion. Day after day, night after night, my real self, my soul, began to emerge. I watched my hair fall out and saw courage, character, and strength grow in. Gone was the self-absorbed beach bunny, and in her place was someone new, but familiar.” MPNA\_0013B*

Identity plots were either interwoven through the biomedical plots, or represented in prologues and epilogues. The detailing of identity plots and the transformational nature of those plots was the product of storytelling choices rather than being related to the nature of the experience; rich identity plots were as likely to be constructed in relation to melanoma diagnosed in its earliest stages when chances of survival are high and quality of life implications are low, as when the diagnosis was advanced and survival beyond five years, or even six months, was unlikely.

### **Normative socio-cultural narratives**

Of the “ready stock of narratives which we appropriate and apply in our everyday social interaction” (Murray 1999:53), the identity plots of many of these stories most significantly reflected the ‘positive transformation’ narrative or “hero journey” that has been identified as recurrent in mythology and in modern popular hero stories (Campbell 1949/2008, Vogler 1985). Also known as a “quest narrative” (Frank 1997), the core features of this archetypal plot are a compelled departure from the ordinary world, a progression through a series of trials and obstacles so momentous as to cause death or change the way life is lived forever, and the acquisition of a ‘boon’ gained through suffering that becomes a legacy should the protagonist die (Lamprell and Braithwaite 2016). In our analysis of our population of melanoma stories, the positive transformation narrative was reflected most particularly in, and was a function of, the epilogue:

*“I am hoping that my story will make people realize that melanoma can happen to anyone, it doesn’t matter race, gender, or age.” MPNA\_023J*

The narrative was also evident in the language of enemy and embattlement used in the stories:

*“I now want to share my experiences with others and give hope to other melanoma warriors.” MPNA\_0014A*

*“I realize that these are my ‘battle scars’.” MPNA\_024E*

**Reflected fiction in lived biomedical plot:** The detailed archetypal plot structure of hero myths formulated first by Campbell and then by Vogler began with a ‘call to adventure’—an inciting incident that marks a turning point for the main character—followed by a ‘refusal of the call’, in which the main character does not respond or is stopped temporarily from responding to the inciting incident. The emplotment of biomedical events in over half (56%, n=120) the illness stories we examined demonstrated this fictional structural element as a lived experience. The

refusals included storytellers delaying seeking medical advice, long waiting periods for specialist appointments and misdiagnoses by doctors:

*"Over the next 6 months, I did see a change in the mole – it was dark, almost black, and raised. Things did start playing on my mind a little bit, but I put it to the back of my mind and continued to use the sunbed."* MPNA\_029D

*"I went to my doctor to have what was a freckle/mole on the top of my foot, which I had noticed had changed. My doctor said that it was normal, it was a nice even colour and even shape, and didn't have any signs of anything bad. So I went away and left it."* MPNA\_019B

### **Time and space in the unfurling story**

Storytime: The written autobiographies in our study population were all retrospective chronicles because the events represented were not occurring in the present for the author/narrator/protagonist. However the stories were structured chronologically, and most represented specific periods of time as meaning-framed, reflecting the issues and psychosocial states of the storytellers while they waited, for example, for test results, for surgery, and for the verdict on treatment outcomes.

*"After my surgery I would be forced to wait for two weeks before hearing whether or not my lymph nodes were 'clear'. Eventually I received a call from my surgeon with the good news that I was cancer-free."* MPNA\_024D

Retrospectivity of clinical representations: There was inconsistent information about the dates the stories were written, and stories differed as to whether the experiences of melanoma were retrospective or current at the time of writing, or whether they conjoined descriptions of previous melanomas with recent recurrence. Given steadily changing knowledge about the disease, and advances in personalised testing and treatment, references to particular kinds of surgeries, chemical treatments and clinical trials were often the only clues as to the historical location of the stories.

Transience of storyteller: Stories occur in the present for the audience who is reading them. The impact of temporality was most relevant audience to these illness stories can only ever know the protagonist/narrator in a particular time of their lives. The protagonist/narrators of these stories may be well, may be sick again or may have died. The time we are with them is the time it takes for us to read their stories, and the time also we take to think about their stories after our

eyes have lifted from the page.

## **DISCUSSION**

We conducted a detailed reading and analysis of 214 web-based stories of melanoma patients' illness. We found that the storytellers of our study population laid out the confronting physical, emotional and existential challenges of their condition and the often uncertain, sometimes distressing and also greatly appreciated paths of their medical treatment. Our aim was to honour their efforts in telling these stories by exploring a narratological analytic framework that would attune us to both the unique and also the shared ways in which people with melanoma represent their experiences

Our study found that the structural storytelling conventions used by these melanoma patients in the creation of their written stories included a chronologically driven plot as an overall organising principle and a story arc that progressively shifts the plot forward, with narrative elements that include: a prologue; exposition of the ordinary world before the action begins; a turning point that sets off the action; rising action leading towards a climax; a climax and falling action; a resolution to the action and; an epilogue that functioned to portray their reflections on their experiences.

We made visible the ways in which patients as storytellers established their narratorship and we established a typology of narrator 'voices' from the grounded analysis of the narrative tone and style. The study gave consideration to whether and how other 'characters' were introduced and found that illness as an entity in their lives played the role of antagonist. The study also explored and identified the ways in which the archetypal positive transformation narrative was reflected in the stories, and positioned the events of the stories and the telling of the stories in context to a temporal literary and medical space.

The outcomes of the study suggest that a focus on storytelling conventions and techniques may be a way to: 1) comprehend melanoma patients experiences in a whole-journey framework; 2) identify the ways in which written storytelling facilitates or limits the articulation of melanoma patients' perceptions of their journeys; 3) provide a means by which researchers can navigate through and identify elements of analysis in rich, thick descriptions of melanoma patients' whole-journey experiences; and 4) characterise the phenomenology of the melanoma experience. By bringing the paradigms of narratology and literature analysis to the interests of narrative inquiry in healthcare, the conventions and

techniques of storytelling offer a starting point for a systematic approach to melanoma patients' stories as research data.

The analysis: To our knowledge this is the first narratologically informed analysis of written illness stories of people with melanoma. Illness narratives have been conceived as a sub-genre of autobiography (Hawkins 1999) and we believe that our findings advance the comprehension of that genre. The identification of common storytelling devices and key plotlines, and our typology of narrators/protagonists, deliver a critical understanding of the ways in which people with the disease represent their healthcare trajectories and express the personal consequences and psychosocial impact of the events of their disease. The reflections of the socio-culturally normative quest narrative in these pathographies have been identified previously in relation to "deep illness" (Frank 1998) such as cancer, but have not been previously examined in relation to melanoma.

Methodological contribution: The findings contribute to the 'toolkit' of methodologies by which qualitative researchers can negotiate written illness stories in general, and specifically pathographies published to the Internet, as sources of data. In combining grounded theory methodology with narratological precepts the constructivist ideology of inductive research (Charmaz 2014) is privileged—storytelling structure and convention can be conceived as adjunct analytic pathways to content analysis.

Limitations: If cultural narratives inform storytelling, so too do 'organisational narratives' (Hawkins 1999:18). The narrative choices that these storytellers made can be assumed to be influenced to greater and lesser degrees by the organisations that sponsor the websites on which they published their stories. Following guidelines and suggestions for content established on these sites, and reading other stories published on these sites, will shape the choices made by these storytellers. Further, since illness narratives are "situated within the social praxis of modern medicine" (Charmaz 2014) narrative representations of illness and patienthood are explicitly or potentially implicitly influenced by the aims of goals of the wider healthcare systems that deliver care to the storytellers. The socio-psycho-political context for storytelling is acknowledged, but not examined in this study.



## CONCLUSION

The power of a narrative process to “structure and guide experiences” (Mattingly 1998:16) is identifiable in this study’s “close reading” (Charon 2006:116) of melanoma illness stories. Through their narrative tone and style, their choices in plot development, their reflections of socio-cultural narratives, and the placing of their experiences in time and space, these storytellers describe and explain their condition, give textured accounts of their healthcare experiences, portray their own and others’ emotions, summarise their practical, philosophical and spiritual conclusions, and represent their imagined futures.

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## Ethical considerations

Approval for the study was for the study was obtained from Macquarie University Human Research Ethics Committee (Humanities-Executive, HREC 5201600665)).

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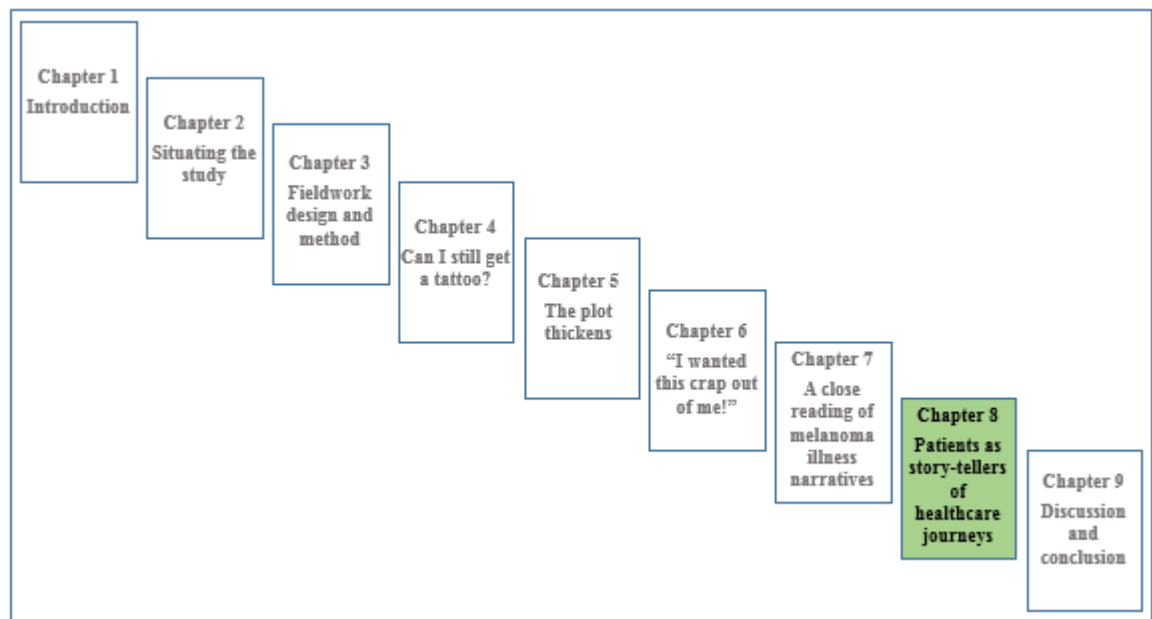
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## 8. Patients as story-tellers of healthcare journeys



The relevance of the archetypal quest narrative to the healthcare experiences of people with melanoma was examined in Chapter 5. In this chapter the quest narrative is explored as a model of story-telling that could enable patients with any kind of health issue to comprehend and articulate their journeys from symptom to outcome. The ideational model offers patients narrative competence in circumstances that may seem inexpressible. As novelist Henry James is credited with saying, "Stories happen to people who know how to tell them."

Page 172 of this thesis has been removed as it contains published material. Please refer to the following citation for details of the article contained in these pages.

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# Patients as story-tellers of healthcare journeys

## Abstract

There are gaps in our comprehension of patients' subjective experiences as they engage with and transit through the healthcare environments implicated in their treatment trajectories. Patients' stories, unlike patient experience data gathered in questionnaires and surveys, express the deeply personal, narrative nature of the journeys that patients take, creating opportunities for qualitative healthcare research. Yet narrative capabilities and propensities vary with individuals, and are affected by the stresses of illness and treatment. This article extends the growing interest in narrative competence training for both practitioners and patients with the investigation of a storytelling model that could facilitate patients to narrate their experiences of healthcare systems. This model is derived from the literary arts. In fiction and autobiography, the journey arc of the central character is often one in which he or she is compelled to leave the comfort of everyday life and face a series of extraordinary events involving challenge and change which forces the character towards practical, intellectual, psychological and philosophical adjustments that define, by the end of the story, the character's 'new normal'. This pattern is known as the 'hero journey'. Its parallels with patients' experiences of healthcare and the way people narrate their stories of illness have long been recognised. We present here a new idea for applying this model as a narrative structure by which patients may construct their stories about being patients.

## Introduction

If 'patient experience' is a topic whose time has come, 'patient journey' is a topic whose time is overdue. There is a gap in our comprehension of patients' personal experiences as they transit through the services that comprise health systems. Yet clinicians and policymakers have a great deal to gain from patients' stories of traversing multiple healthcare environments, especially when health conditions take patients into chronic states. Supporting patients to narrate their experiences across silos of care, using a narrative model based on the classic journey arc of fictional characters, may be a useful approach to closing the gap.

Expertise in the narrative construction of personal journeys is well established in the literary arts. This expertise can inform scholarship in the inter-disciplinary fields of *narrative medicine* and *health humanities*, which look to the structure of fictional texts, amongst other forms of creative expression[1, 2] to understand

experiences of patients [3] and to develop narrative competence in experiential storytelling and story-listening [4].

In this context, the relevance of the fictional quest narrative, or hero journey, to the way people narrate their illness journeys has been conceptually and empirically broached[5-10]. The focus of this attention has been directed to the use of the quest narrative structure as a means by which researchers and clinicians can analyse patients' stories, and identify the personal transitions as people move through the events of their disease and medical trajectories.

### **The quest narrative as a tool for narrative competence**

The structure of the quest narrative may have another use—as a model that facilitates patients to tell their stories. The narrative competence to *tell* stories of illness well is as important for the relationship between medical practitioners and patients, and for knowledge transfer between patients and policy-makers, as the importance of *listening* well to stories of illness [11]. How patients narratively perceive and convey their experiences varies with narrative capability and propensity [3] and also with the trauma of illness and treatment; the 'wounded storyteller' [8] may struggle with the narrative confidence to speak of sickness and patienthood. A patient-journey storytelling model may be an apt tool in facilitating patients to narrate their experiences.

In the narrative arc of the fictional hero journey [12-14] the central character undergoes three epic transitions: he or she is compelled to leave the comfort of everyday life in search of resolution to a crisis, or attainment of a critical goal; he or she then faces a series of extraordinary events involving frustration, challenge and change involving a special, strange world; and finally, a resolution is achieved, or the goal is obtained, and the character returns, though forever changed, to the ordinary world that was the starting point of the story. **Table 1** provides a descriptive account of these stages and sets out the analogous patient experience of the healthcare journey. The incremental impact of challenge and change on the protagonist is portrayed through the narrator's descriptions that intertwine the 'outer' action—the events of the story—with the 'inner' action—the character's thoughts and feelings in response to those events. The return to the ordinary world is an intrinsic feature of the model. This is when the consequences of the story become evident, when the narrator can summarise and draw attention to the 'new normal' that has resulted from the impact of change. Fictional characters as seemingly disparate as Neo in *The Matrix*, Frodo Baggins in *The Lord of the Rings*,

007 in the James Bond franchise, and Katniss Everdeen in *The Hunger Games* series, follow this ubiquitous template.

The parallels with patients' experiences of healthcare are particularly evident in cases of critical and chronic health conditions when patients make complex and transitory journeys across providers and institutions. These patients leave the comfort of everyday life as one state of health transforms into another, and they face a series of extraordinary events that include accommodating to different healthcare settings, looking to strangers for knowledge, advice and support, learning medical terminology and healthcare 'speak', dealing with the impact of appointments, hospital stays and treatment outcomes on family, work and social life, and managing the evolving thoughts and feelings that are occurring in response to each new encounter.

### **Application of the model**

In fiction, the hero journey model also typically includes a cast of seven archetypal secondary characters that a protagonist is likely to meet. Derived from the precepts of psychologist Carl Gustav Jung, these archetypes are: mentor, herald, threshold guardians, allies, shadows, shapeshifters and tricksters. These are types of people, and also types of events, that act to advise and support, or sometimes block, delay or mislead, the main character. In the patient's journey, these archetypes may be represented in the interactions with clinicians, administrative and facility staff, and also in receiving the results of tests, the application of medicines, and the making of appointments. **Table 2** provides a guideline to the role each of these archetypal characters play in the fictional protagonist's journey, and sets out a potential analogy with the patient's experience of the healthcare journey.

As a narrative structure through which patients could construct their stories about their illness, the three key structural elements of the patient's narration would then be:

- the transformation from what is a personally normal state of health into an abnormal state of health, and the healthcare events that surround signs and symptoms, diagnosis and decision-making on treatment;
- encounters with healthcare services during the critical episodes of treatment;
- experiences of follow-up care services and ongoing illness management.



In the patient's storytelling of a healthcare journey, as in the story of a fictional character's journey, the third component is intrinsic—it provides the opportunity for patients to narrate their experiences of ongoing interaction with healthcare beyond the critical treatment period, and into the “new normal” that is now everyday life. That new normal may comprise rehabilitation, oncological treatment, insulin management, physiotherapy and sometimes palliative care.

### **Patients as heroes?**

There is an elephant in the room when considering the appropriation of a quest narrative structure as a model for patient-journey storytelling. The hero journey narrative transitions a protagonist from ordinary person to hero. It may not be appropriate to impose upon patients that they characterise themselves as high achieving and consistently do-gooding in the stories they tell of their experiences. While some patients do perceive meaning in the trials and obstacles of their healthcare experiences [8, 15, 16]; others may not.

The twist, however, is that regardless of whether the patient-as-protagonist is a heroic figure, the patient-as-storyteller achieves a special feat by being the “voice of the experience and the voice of the expert” [17]. Patients-as-storytellers bring the boon of experiential knowledge to their audience community of clinicians, policy-makers, and other patients [11]. In this sense, they are heroes, but cannot be imposed upon to characterise themselves in this way.

### **Contribution to future models of care**

The patient's perspective on service delivery is now recognised as evidence on which to develop policy on quality [18, 19] and safety [20, 21] in healthcare systems. Accounts of patient experience are considered integral to programs that enhance clinical competence [22, 23] and that endeavour to engage people with their own health [24, 25]. Programs designed to account for and assess medical episodes in individual institutions, and surveys intended to collect statistical data on patient satisfaction even across spectrums of settings, do not comprehend the deeply personal, narrative nature of the journeys that patients take as they move through healthcare providers [26]. This is the value of patients' stories [3, 11, 27, 28].

The appropriation of the hero journey model as a narrative structure for patients facilitates narrative competence in wrangling complex, deeply-felt experiences across silos of care over periods of time. It provides a relevant model of how to

store such experiences. Reframed as a patient-journey model, this is a compelling means by which patients can narrate their whole-healthcare experiences to audiences of future patients, researchers, healthcare providers, and policymakers. As a companion tool to cross-sectional patient satisfaction or experience measures, or interventional studies, the patient-journey narrative model could enable fresh insights into patients' experiences of transitions between community, diagnostic, treatment, and rehabilitation environments. This could be decisive information in improving future models of care.

## Appendices

Campbell articulated seventeen phases of the archetypal life-challenging journey, laid out in three broad stages that he called, 'Departure', 'Initiation', and 'Return'. The Jungian psychosocial framework of interpretation Campbell used to define some of the phases of the protagonist's journey no longer have cultural relevance, or are no longer culturally acceptable, such as symbols of woman-as-temptress, and father-as-ogre. Vogler modernised and condensed Campbell's material into twelve phases within three synonymous stages that he conceptualised, in literary terms, as Act I, Act II, and Act III. [Table 1](#) sets out an appropriated structure from Vogler's version of the three-stage model, mapped to a potential analogy with the patient journey experience. [Table 2](#) sets out the archetypal characters that may appear in the narrative, as established in Vogler's model.

**Table 1:** A descriptive analysis of Vogler's version of the model(Vogler 1992) mapped to the patient journey experience.

Scene	Description	Patient journey analogy
<b>First Stage: Act One</b>		
<b>1. Ordinary World</b>	The central character is introduced in the context of a very recent polarity between the ordinary self in the Ordinary World, and something that is pulling in a different direction and causing stress.	<i>A person, living their normal life, experiences injury or illness, or notices a symptom.</i>
<b>2. Call to adventure</b>	Something shakes up the situation, either from external pressures or from something rising up from deep within, so the central character must face the beginnings of change.	<i>The person is moved to act, perhaps by an increase in the intensity of the injury or symptom, or a meeting with someone who has had similar issues.</i>
<b>3. Refusal of the call</b>	The central character, even briefly, feels a fear of the unknown and thinks about turning away from the adventure, or another character expresses the uncertainty and danger ahead.	<i>Moments of hesitation—the person senses fear or rationalises a desire to postpone dealing with their condition.</i>
<b>4. Meeting with the</b>	The central character meets an	<i>The person encounters a gateway</i>

<b>mentor</b>	experienced person who gives training, equipment, or advice that will help on the journey.	<i>clinician, usually a GP; there may be a diagnosis, tests, a biopsy, or a referral onto specialists for further investigation.</i>
<b>5. Crossing the threshold</b>	The central character feels there is no option but to commit to leaving the Ordinary World and entering the Special World—a new region with unfamiliar rules and values.	<i>The diagnosis pushes the person over the threshold—the person has become a patient.</i>
<b>End of first stage, beginning of Act Two</b>		
<b>6. Tests, allies and enemies</b>	The central character is tested with new challenges and begins to sort out the rules of the Special World and also begins to understand where allegiances and counter-allegiances lie.	<i>The patient embarks on treatment, or further appointments, tests, and biopsies relevant to the diagnosis, during which he or she faces the idiosyncrasies of different health care settings and stakeholders. Lack of knowledge, bewilderment, and threats, abound.</i>
<b>7. Approach to the innermost cave</b>	The central character comes to the edge of a truly dangerous place.	<i>Now more aware of all that is involved in treatment and/or further diagnoses, the patient must embrace their fears, and make a commitment to treatment and ongoing management.</i>
<b>8. Supreme ordeal</b>	The central character goes into the ‘belly of the whale’, facing his or her greatest fear.	<i>The patient endures the treatment option that will alleviate symptoms, prevent further illness, or indeed save his or her life, bringing all the fears and uncertainties to a critical point.</i>
<b>9. Reward</b>	The central character takes possession of a treasure; metaphysically the reward is knowing that he or she is going to be well, or has survived, if only for now.	<i>The patient is granted clarity about the future.</i>
<b>End of second stage, beginning of Act Three</b>		
<b>10. The road back</b>	The hero realises that the Special World must be left behind and the journey must be made back to the Ordinary World.	<i>The patient is completing his or her time on the medical journey, and must begin to conceive of life back in the original environment.</i>
<b>11. Resurrection</b>	At the climax, the hero is tested once more on the threshold of home. By the hero’s actions, the polarities that were in conflict at the beginning are finally resolved.	<i>While the injury or symptom is perhaps now settled, the patient faces a new sense of identity for the future—the diagnosis may have indicated an ongoing issue or made the patient aware of his or her fragility and mortality. Treatment may have had ill effects that must now be dealt with.</i>
<b>12. Return with elixir</b>	The hero returns home or continues the journey, bearing some element of the treasure that has the power to transform the world as the hero has been transformed.	<i>The patient shares the lessons learned from his or her experience—perhaps protecting others with newfound knowledge about a health condition or offering metaphysical advice to family and friends about their fragility or mortality.</i>

**Table 2.** The hero journey model identifies archetypal stakeholders that recur in hero journey stories. This table maps out a potential correlation with stakeholders in the patient journey experience.

Archetype	Description	Patient journey analogy
<b>Central character/hero</b>	Central figures—everyone is the hero of his or her own story.	Patients.
<b>Herald</b>	Person or event that brings the Call to Adventure.	Symptoms, self, other, GP.
<b>Mentors</b>	Advice-givers, or own guiding principles.	Medical professionals, other clinicians, others with similar illness experiences.
<b>Shadows</b>	People or events that act as villains and enemies, or perhaps the enemy within.	Administrative obstacles, unclear clinical options, personal fears.
<b>Threshold guardians</b>	Forces that stand in the way at critical points, including professional gatekeepers, or own fears and doubts.	Medical receptionists, lack of access, overdue test results, personal concerns.
<b>Shapeshifters</b>	People or events that keep changing (or own perceptions that keep changing).	Differing providers, varying perspectives on patient options, unclear instructions and advice, delays and rescheduled appointments.
<b>Tricksters</b>	Mischief-makers, or own mischievous subconscious.	False diagnoses, medication that doesn't work, or that causes allergic reactions.
<b>Allies</b>	Characters who help the hero through the journey.	Medical professionals, friends and family.

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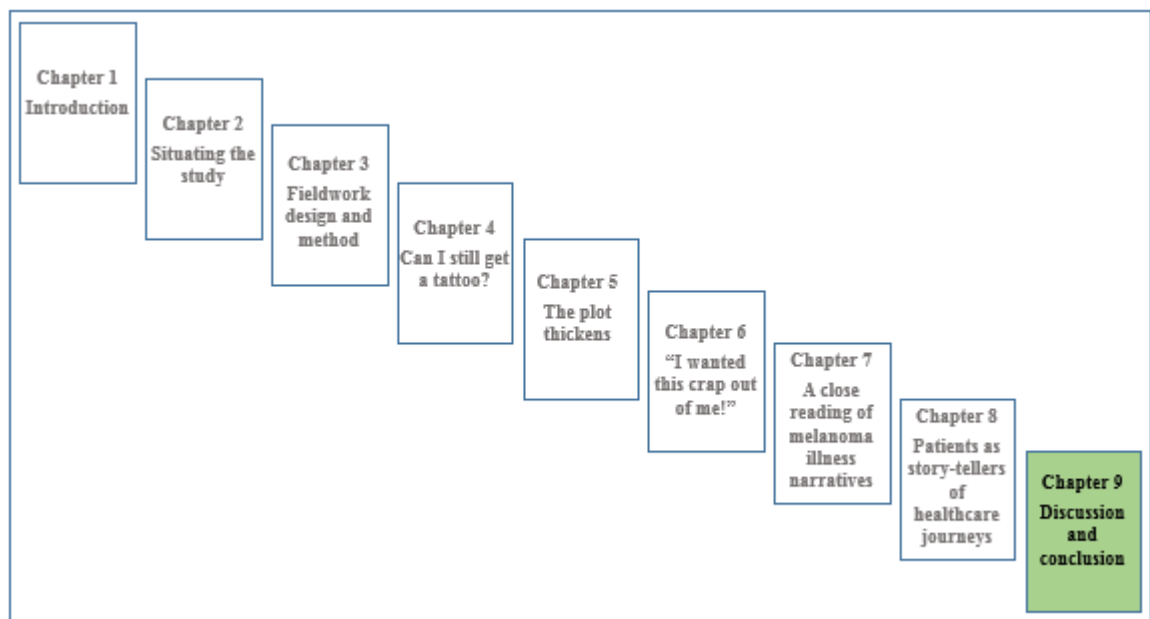
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## **Part Three**

### Chapter 9: Discussion and Conclusion

## 9 Discussion and conclusion



The study, I believe, is the first to investigate narrative as a system of comprehending and articulating the patient's perspective on melanoma patient journey. The study initiates the conversation about narrative emplotment as a means of understanding patient experience from the perspective of the patient, and meta-narrative as a means of facilitating a longitudinal, qualitative perspective on melanoma care. It is the only study to consider both content and structure in the narrative telling of melanoma patient experience by patients and the retelling of melanoma patient experience by researchers.

Moreover, the study answered the primary research question and responded to the radial aims and objectives set out in the introductory chapter. Based on the cross-disciplinary precepts identified in Chapter 2, I investigated the healthcare experiences of people with melanoma and facilitated meta-narrative views of their patient journeys by undertaking two modes of narrative inquiry and four sets of analyses that resulted in four meta-narrative perspectives. I completed the study with a fifth meta-narrative perspective of patient journey in general.

### **Ethnographic inquiry**

The first mode of inquiry was an ethnographic study of a group of people with advanced and metastatic melanoma. I followed these people as they moved through the episodes of medical management and disease progression that eventuated in either the end of their lives or a new way of living. In the first analysis of the narrative texts developed from this inquiry I took a thematic view of components of the melanoma patient journey, focusing on themes grounded in the data. I identified a meta-narrative

in which the key phases of melanoma patient experience comprise transitions between the initiation of healthcare, identification of the disease, action taken to manage the disease, adaption to life after treatment and, potentially in circumstances of recurrence, onto a repetition of the narrative plot. Each phase of this meta-narrative featured common sets of healthcare experiences.

In a second analysis of the same narrative texts developed from this inquiry I took a whole story view of melanoma patient journey, focusing on plot. This analysis mapped the plot of melanoma patients' trajectories to the archetypal plot of the quest narrative that underpins culturally held views of illness and patienthood. The analysis identified a meta-narrative in which the key phases of patient experience comprise transitions between the ordinary world of the patient's life, the special world of the healthcare system, the new normal of life after treatment and again, potentially in circumstances of recurrence, onto a repetition of the narrative plot. The phases of this meta-narrative featured common turning points—events that would move the narrative in a new direction.

### **Analysis of illness narratives**

I then investigated 214 personal accounts of melanoma journeys published to the Internet. Again I undertook two analyses of these narrative texts. The first analysis was a thematic view of components of the melanoma patient journey, focusing on themes related to met and unmet needs for supportive care. This analysis was grounded in the data and identified a meta-narrative in which the key phases of melanoma patient experience comprise transitions between the lead-up to diagnosis, diagnosis treatment and recovery, and post-treatment and recurrence. Each phase of this meta-narrative featured common impact-critical periods of need for supportive care.

In the second analysis of the same narrative texts, I took a whole story view of the melanoma patient journey, focusing on the construction of stories about melanoma patient journey. This analysis was framed by four key elements of narrative construction: character, grounded plot, archetypal plot and setting (time and space). This analysis identified a meta-narrative of storytelling conventions in the autobiographical domains of melanoma patient journey.

### **Normative model of patient journey**

The radial aims and objectives I set out in the introductory chapter of this thesis were also realised in an exploration of the archetypal quest narrative as a model by which patients could become storytellers of their healthcare journeys. I mapped generic longitudinal patient experiences to the quest narrative plot, and the identity of patient to



the identity of protagonist, as a means of making healthcare experiences tellable for patients who struggle with narrative chaos. Using the ‘ready-made’ narrative structure of this normative narrative model, patients potentially could articulate personally unique and collectively common perceptions and reflections of medical and ancillary healthcare services and healthcare providers.

### **Methodological contribution of the study**

Pinnegar and Daynes note that narrative inquiry is not only a commitment to a style of research: it is also a commitment to “the creation of an environment in which narrative inquiry can flourish (Pinnegar and Daynes 2006:3). The study was part of the overall strategy of the thesis to investigate and establish a cross-disciplinary narrative foundation for melanoma patient experience research, through the concept of meta-narratives of patient journey. The set of precepts derived from narrative inquiry, narrative medicine and medical humanities in Chapter 2 provided the methodological competence to push into unattended narrative spaces of melanoma patient experience research. The result was a comprehensively meta-narrative perspective on patients’ experiences of the melanoma patient journey and a foregrounding of narrative as a productive system for understanding melanoma patient experience. As an outcome, the study identified cross-disciplinary narrative heuristics by which to:

- obtain rich qualitative data on the personal impact of healthcare services on melanoma patients
- engage empathically with the challenges melanoma patients face in taking their personal quests for wellness into the public domain of healthcare
- conceive of the narrative devices and socio-cultural narrative models that melanoma patients use in the expression of their perceptions
- identify analogous, pragmatic metaphors for the challenges people with melanoma face when they enter the realm of healthcare
- design qualitative research methods that account for the whole plot of the melanoma patient journey and have depth of experiential scope
- respond to the concern for the translation of research data into policy and practice by delivering information in a format that has relevance to the patient populations under study.

### **9.1 Aggregate findings of the study**

In light of the imperative to translate growing amounts of data into policy and practice, I looked to the aggregated findings of the triangulated research to understand how and in

what ways it collectively mapped to the extant qualitative literature on melanoma patient experience that was identified and reviewed in Chapter 2. The following discussion comprises: i) a comparison of the healthcare experiences and patient journey structures identified in the ethnographic fieldwork project and the illness narrative project, and ii) a comparison of the aggregated findings of both research projects to the existing literature. In this discussion, I refer to the fieldwork project comprised in the study as ‘Project A’ and the illness narrative project comprised in the study as ‘Project B’. The points of references are detailed in Table 21.

**Table 21:** Points of reference to each of the investigative frameworks of the study

Study	Relevant chapter	Reference
Ethnographic study of people with melanoma	Chapter 4 ‘Can I still get a tattoo?’	Project A
Written personal accounts of melanoma	Chapter 6 ‘I wanted this crap out of me!’	Project B

In Tables 22 to 25 I produce an aggregate view of the findings of Projects A and B of the study, and identify the key phases of perspectives and experiences that were identified in each of the two data sources. The discussion that follows considers how they ‘fit’ with each other in characterising the melanoma patient journey.

**Table 22:** First phase of the patient journey: a comparison of thematic findings from two data sources

Project A: ‘Initiation’		Project B: ‘Lead-up to diagnosis’	
Patient-led delays	Rationalisation of health disturbances eg thinking a health issue is ‘just stress’ or too much going on in life, waiting for an upcoming appointment  Having been told pain is normal for a particular health condition  Low sensitivity to or awareness of melanoma recurrence & perception of being ‘clear’ of melanoma	Patient-led delays	Rationalisation of health disturbances & pain eg serious illness is ‘something that happens to someone else’ or ‘too busy’  Incompatibility of own skin changes in comparison with pictures shown in melanoma awareness campaigns
Clinician-led delays	Low healthcare provider awareness of risk of recurrence	Clinician-led delays	Wait times for specialist appointment Missed diagnoses Conflict between patient and physician about the need for further investigation of a symptom

**Table 23:** Second phase of the patient journey: a comparison of thematic findings from two data sources

Project A: 'Identification'		Project B: 'Diagnosis, treatment and recovery'	
Impact of investigations & consultations	<p>Significant logistical &amp; time commitment in appointments</p> <p>Infection &amp; pain from open lung biopsy</p> <p>Physical difficulties getting to appointments &amp; managing movement during scans</p> <p>Appreciation of scans and consultations scheduled to occur in the one location or on the one day.</p>	Co-ordination of healthcare services	Appreciation of coordination of appointments made for tests, consultations with oncologists and surgeons, and surgery.
Information pathways & knowledge absorption about diagnosis	<p>Appreciation of detailed explanations of scanning equipment and visually represented results</p> <p>Confusion about names and functions of types of scans</p> <p>Difficulties of staying focused during consultations</p> <p>Reliance on information provided by hospital and clinicians</p> <p>Concern with the negative implications of 'knowing too much'</p>		
Impacts of diagnosis	<p>Desire to be given a timeframe for survival</p> <p>Frustration at clinicians' explanations of prognosis as complex</p> <p>Impact related to expectations of recurrence eg some expecting a recurrence, others shocked</p> <p>Surprise at the role of 'luck' in finding the melanomas</p> <p>Confusion when tumours were assumed to be melanoma but could not be confirmed</p>	Impact of news of the diagnosis	<p>Impact of communication with clinic receptionists to organise test result appointments</p> <p>Physician choices in tone and wording in delivery of test results</p> <p>Negative impact of contrast between earlier reassurance &amp; subsequent diagnosis</p> <p>Emotional &amp; physiological impact of news depending on physician style and tone</p> <p>Impact of hearing a diagnosis on the capacity to absorb information about diagnosis and treatment options</p>

**Table 24:** Third phase of the patient journey: a comparison of thematic findings from two data sources

Project A: 'Action'		Project B: 'Diagnosis, treatment and recovery'	
Information pathways	<p>Vague understanding of the BRAF concept and what testing or results means</p> <p>Appreciation for pamphlets about treatment</p> <p>Appreciation of tours of chemo-therapy clinics</p>	Information pathways	<p>Need for more information about the likely effects of chemical therapies</p> <p>Concern with lack of preparation for clinical trials</p>
Treatment decisions	<p>Preference for non-collaborative decision-making; physicians asked to make the choice</p> <p>Decision to 'do what it takes'</p> <p>Going into clinical trials for the sake of future generations and need to be proactive in sourcing clinical trials</p> <p>Want physicians to make decisions</p> <p>Make strategic choices in healthcare providers then do what they say</p> <p>Decision limbo until BRAF test results come back causes frustration</p> <p>Consideration of second opinion on treatment options</p>	Treatment decision	<p>Desire for help in finding, understanding and making decisions about alternative treatment options</p>
Physical & psychosocial experiences of treatment	<p>Rationalisation of side effects in light of the 'end-goal'</p> <p>Concern about mentioning side effects in case taken off treatment or removed from clinical trial</p> <p>Significant side effects in clinical trial and need to embark on second trial for drug to manage side effects</p> <p>Scheduled chemo-treatments become routine and relationships are developed with clinic staff</p> <p>Significant logistical and time commitment in attending clinical trial over years</p>	Surgery & recovery	<p>Frustration at long wait times for surgery</p> <p>Shock about the size and impact of the surgical excisions</p> <p>Surprise at the complexity of the recovery process</p> <p>Frustration and concern about long wait times for pathology</p> <p>More support required in psychosocial adjustments to 'successes' and 'failures' of treatments and clinical trials</p> <p>Rationalisation of side effects in light of the 'end-goal'</p>

**Table 25:** Final phase of the patient journey: a comparison of thematic findings from two data sources

Project A: 'Adaptation'		Project B: 'Post-treatment and recurrence'	
Health management related to surgery and medication	<p>Organisation of lifestyle around management of pain and discomfort of lymphoedema eg pumping out fluid each day and taking pump on vacation</p> <p>Commitment to and appreciation of long-term relationships with healthcare providers involved in management of lymphoedema</p> <p>Scheduling each day around large amounts of medication</p> <p>Ongoing side effects of medication</p>	Long-term physical consequences	<p>Managing change in lifestyle because of pain and discomfort of lymphoedema and other consequences such as severe peripheral neuropathy</p> <p>Ongoing side effects of medication</p> <p>Rationalising long-term side effects and consequences of surgery and medication against positive outcome of survival</p>
Disease surveillance and psychosocial management of potential recurrence	<p>Making personal commitment to regular scans regardless of logistical issues.</p> <p>Planning vacations and life events around timing of scans</p> <p>Commitment to and appreciation of long-term relationship with oncologist and other healthcare providers involved in surveillance</p> <p>Constant negotiation of feelings about high risk of recurrence</p>	Ongoing checkups	<p>Acknowledgement of lifelong dependence on healthcare for evidence of health</p> <p>Acknowledgement of lifelong need for support to manage anxiety about recurrence and metastases</p> <p>Unrequited expectations that clinicians in follow-up consultations will deal with psychosocial issues relating to fear of recurrence</p>
Dependence on healthcare services for personal life decisions	Vacation periods, cosmetic surgeries and permanent 'adornments' such as tattoos must be negotiated with oncologist		
		Recurrence and metastases: the journey begins again	Symptoms less often skin-related and include lumps, pain, headaches, mobility issues and organ function impairment.

### Discussion of similarities and differences in findings

A common goal for both projects was the characterisation of a meta-narrative of patient journey. In both projects, a thematic analysis grounded in the data enabled key content themes to emerge. These themes were then collectively identified into domains, which were thematically categorised into progressive, periodic plot structures. In Project A, a

plot structure with four key periods of patient journey was identified. In Project B, a plot structure with three key periods of patient journey was identified.

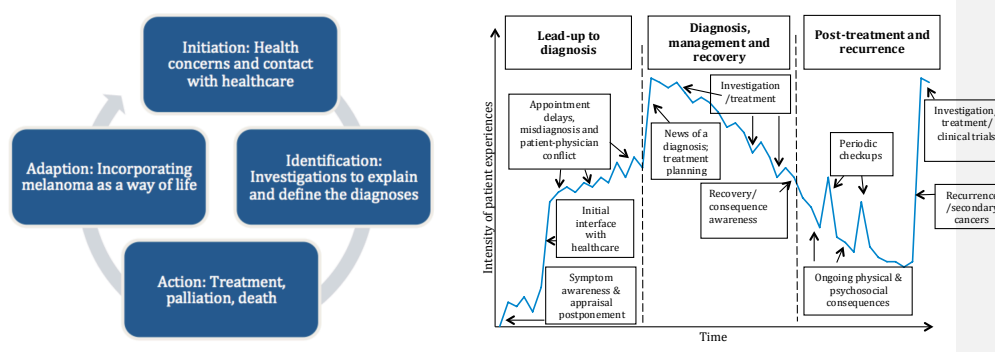
The perspective of the meta-narrative in Project A is that of the patient and engages with what it is like to move through the healthcare system: a journey is initiated (awareness of health concerns and contact with healthcare), identification is sought (investigations to explain and define the diagnosis), action is taken (undergoing treatment and palliation) and one has to adapt to new circumstances (having survived, then incorporating melanoma as a way of life). The perspective of the meta-narrative in Project B is that of the healthcare system and engages with the sequences of clinical management: the lead-up to diagnosis as a function of health-seeking behaviour; diagnosis and treatment of the patients' disease and managing their recovery from treatment; and then identifying the role that healthcare plays and needs to play in the post-treatment experience and in recurrence of the disease.

The differences in the perspectives of each meta-narrative relate to the specific goals of data collection and analysis. The research question in Project A related to melanoma patients' perceptions of healthcare experiences. The research question in Project B related to melanoma patients' perceptions of supportive care experiences. Thus the *nature* of patient experience was privileged in Project A, and the *kind and extent* of experience was privileged in Project B. Whereas in Project A, the data-set comprised any perceptions of healthcare expressed by study participants and also my observations, in Project B the data set comprised met and unmet needs for supportive care described in the written illness narratives. The two frameworks arrived at very different plot structures, represented in the visualisations of Figure 3. The differences may also reflect my deep engagement with the study population in Project A through ethnographic fieldwork, and my contained engagement with the storytellers in Project B, despite the practices of affiliation that were undertaken as part of the methodological commitment to the project.

The plot structure that emerged from the data in Project A, as noted in Chapter 4, is circular, representing the patient-centric view of the potential for recurrence in the future. Recurrence would call on a person with melanoma to begin again, to cycle through the phases of initiation, identification, action and hopefully adaption. The view offered in that plot structure is patient journey as a past, present and future in a person's life. In contrast, the emplotment of patient journey in Project B is linear and features the impact-critical periods when healthcare is most and least required. The potential for recurrence of melanoma is a continuum of healthcare services. These plot structures

characterise different meta-narratives of melanoma patient journeys, featuring the progression of the melanoma patient from symptom identification to outcome and into the imagined future. The differences offer patients and researchers different comprehensions of the melanoma patient journey.

**Figure 3:** The representations of plot structures identified in Projects A (left) and B (right)



### Comparison of findings with studies identified in literature review

Despite differences between the meta-narratives produced in Projects A and B, the data were broadly synthesised in the side-by-side text tabulation. It was possible to see where the two findings were differentiated, and also where the findings of one project ‘plugged’ a gap left by another. Drawn together as a collective set, these findings can then be compared to the perceptions of melanoma healthcare identified in the literature review. It becomes possible then to understand where Projects A and B of the present study have supported the work of other researchers and where new contributions have been made. In the literature review in Chapter 2, the existing data on melanoma patients’ perceptions of healthcare experiences were thematically organised into three key progressive segments of patient journey and one global category covering outset-to-outcome themes that together established a meta-narrative view of what is known about melanoma patients’ perceptions of care. This meta-narrative view is used in the following comparative synthesis of findings from the present study and findings identified in the existing studies (Table 26).

**Table 26:** Comparative synthesis of findings identified in the literature review and findings from the present study

	Literature review findings	Findings of the present study
<b>Symptom identification to diagnosis</b>	Time lapses between symptom identification and help-seeking of 0–1.5 months in earlier stages of the disease and 2–25 months in later stages.	Wait times of 1.5 months to 4 months identified in the present study; not attributed to stages of melanoma.

	Patterns of symptoms different between early and late stages of disease.	In recurrence and metastases, lumps and pain are more likely symptoms than skin changes.
	Help-seeking can be a time-consuming personal negotiation of concerns.	Identified in the present study that 19% of written illness narratives featured patient-led delays.
	Patient-led delays occur because of: fear of diagnosis; personal health identity eg serious illness happens to other people; mismatch between symptoms and pictures of melanoma; normalisation of symptoms over time; and preference not to waste a physician's time. Help-seeking facilitated by family and friends, previous history of melanoma and knowledge of others' experiences; fear about melanoma. Help-seeking may be influenced by gender.	Identified in the present study, though gender differences not a feature. Additionally, patient-led delays may occur in people with comorbid health conditions because they identify symptoms as part of their existing situation. Further, people with previous melanomas who have been 'cleared' by their oncologists may not act on non-skin related symptoms.
	Delays in diagnosis can be caused by lack of recognition of symptoms by physicians and poor communication about when and how to follow up on a suspicious symptom.	Identified in the present study that 34% of written illness narratives featured clinician-led delays in diagnosis. Additionally, clinician-led delays may occur because physicians may have low awareness of symptoms of early melanoma and melanoma recurrence. Wait times for specialist appointments impact time to diagnosis. Patients and physicians may disagree about the need for further investigation of a symptom.
	Not identified in the existing qualitative literature.	Tests and investigations may have a substantial impact on patients with regards to: logistical and time commitments; effects of biopsies; difficulties due to comorbid health conditions. Patients value support in the co-ordination of appointments. Patient may struggle to remember and comprehend the names and functions of scans and other tests.
	Not identified in the existing qualitative literature.	The way that a diagnosis is delivered may have a substantial impact with regards to: physician's choices in tone and wording; contrast between earlier reassurances about symptoms and diagnosis; and capacity to comprehend what is being said.
	Reliable prognostic information available for certain melanomas may not relieve uncertainty about the future and may engender uncertainty.	Identified in the present study that the complexities of providing a reliable prognosis for most kinds of melanoma can be a cause of frustration for melanoma patients; they may want to be given a clear timeframe for survival and may experience frustration at clinicians' explanations of prognosis as a complex undertaking.
	Seeking information about melanoma and prognosis may not always resolve uncertainty and could engender it. Patients may manage their uncertainties by trusting clinicians and the health-care system to provide timely, relevant information.	Identified in the present study that patients may have difficulties comprehending information provided by clinicians, and may feel they do not have time to resolve queries; they value clinicians who take time with explanations and use concise 'layman' language.
<b>Diagnosis through to treatment</b>	Not identified in the existing qualitative literature.	People with melanoma may prefer their clinicians to make decisions about treatments. Alternatively, people may want their clinicians to be open to second opinions and alternative treatment options, and also to be knowledgeable about current relevant clinical



		trials.
	Not identified in the existing qualitative literature.	Wait times for BRAF results, surgery and clinical trials may cause substantial frustration.
	People with melanoma may feel they have not been given enough preparatory information to understand the procedures and immediate effects of surgery.	Identified in the present study. Additionally, melanoma patients may value being introduced to staff in the clinics where they will undergo repeated or long-term treatments.
	People with melanoma may not be prepared for the extent of scarring and functional impairment from surgery, the amount of time needed for recovery and the differences between their expectations of surgical wounds and the expectations of surgeons.	Identified in the present study. Additionally, melanoma patients may not be prepared for long wait times for pathology. Further, they may require support to cope with the successes and failures of surgery.
	Not identified in the existing qualitative literature.	People undergoing chemical therapies for melanoma may lack clarity about side effects and may be concerned to mention side effects in case they are taken off the treatment. Further, their criteria for success and failure of treatment may be mismatched with the criteria used by their oncologists.
<b>Post-treatment</b>	People with melanoma may not be prepared for, and may feel unsupported in managing, non-specific symptoms and fatigue resulting from treatment.	Not identified in the present study
	There may be uncertainty about schedules for follow-up reviews and what to expect in follow-up reviews. People with melanoma may expect and value a clinical skin examination and may perceived it as a means of reassurance about recurrence. They may expect to discuss fear of recurrence and other psychosocial issues.	Identified in the present study that there may be uncertainty about continuity of follow-up care, particularly whether a follow-up review will be with the treating specialist or with a 'subordinate' clinician. Further, there may be frustration if appointments are not long enough to move through queries and have issues resolved.
	Follow-up reviews may have logistical and time-commitment implications for people with melanoma. Melanoma patients may accept longer periods of time between reviews if given access to unscheduled appointment times.	Identified in the present study as a commitment to, and appreciation for, long-term relationships with healthcare providers. Additionally, high-risk melanoma patients may perceive follow-up reviews as crucial to their survival.
	Identified in the outset-to-outcome studies.	In 'life after treatment', melanoma patients may perceive an overall dependency on their consulting specialists to: protect them from recurrence; guide decisions on personal issues such as vacations and other surgeries; manage the ongoing effects of surgery, chemotherapies and clinical trials; and be available to resolve any health and psychosocial concerns that arise in relation to being a melanoma patient.
	A diagnosis of recurrence may be less of a major shock for people who have had melanoma, though they may be angry and perceive uncertainty about treatment options.	Identified in the present study that people diagnosed with a recurrence may be devastated and highly fearful about their prognosis.
<b>Outset-to-outcome</b>	People with melanoma may have issues with the provision of information that is relevant to their personal situation, appropriately worded or visualised for their level of comprehension and presented at times relevant to their phase of the patient	Identified in the present study in every phase of the patient journey.

	journey.	
	Melanoma patients negotiate changing emotional and psychosocial issues throughout the patient journey. They are unlikely to seek professional psychosocial support at any time and are unlikely to be offered it in the context of the medical management of their disease.	Identified in the present study that people with melanoma have expectations that healthcare providers involved in the melanoma patient journey will have awareness of, and the capacity and skills to deal with, the emotional and psychosocial issues associated with diagnosis, treatment and post-treatment life.

## 9.2 Contribution to what is known about melanoma patient experience

In the literature review in Chapter 2, the existing data on melanoma patients' perceptions of healthcare experiences were thematically organised into three key progressive segments of patient journey and one global category covering outset-to-outcome themes that together established a meta-narrative view of what is known about melanoma patients' perceptions of care. When directly synthesised into this same meta-narrative view, the findings of Projects A and B of the present study largely correspond with what is known, with some key differences that distinguish the contribution of the present study.

### Contribution to what is known about diagnostic experiences

The contribution of the present study features, firstly, issues related to comorbid health conditions. In the present study some people identified a symptom of melanoma as another symptom of their existing health condition, with the result that they did not seek timely medical advice. Some people with comorbid conditions who did seek medical advice for a symptom struggled with their limited capacity to manage the scans and tests required for diagnosis. Perceptions of those investigations featured as another contribution of the present study. Study participants noted the logistical challenges and time commitments of undertaking diagnostic investigations for melanoma. They expressed difficulties comprehending the names and functions of tests, often despite explanations from their physicians, and described their lack of preparation for the physical and psychosocial disruption of biopsies.

A further contribution of this study in the context of the diagnostic period related to the perceptions of people with previous melanomas who had been 'cleared' by their oncologists. Belief that their disease was gone prevented some people in the study from being vigilant about recurrence, particularly in relation to non-skin related symptoms of recurrence such as lumps, headaches and internal pain. Perceptions of the circumstances in which healthcare providers delivered the news of diagnosis, and the impact of healthcare providers' choices of tone and timing in delivering the news, comprised another contribution of this study. Of note was the dissonance between being told by a

physician that a symptom was unlikely to be melanoma and subsequently receiving the news.

### **Contribution to what is known about treatment experiences**

The present study was also distinguished from existing literature in identifying patients' perceptions of treatment decision-making. In the present study, some people preferred their clinicians to make decisions about treatments; while they appreciated information and explanation, and wanted opportunities to ask questions, they perceived that their physicians had the expertise about treatment options and the knowledge of their health required to move forward with particular treatments. Other perceptions of treatment decision-making identified in the study related to physicians' openness to facilitating second opinions, knowledge of relevant current clinical trials and awareness of complementary therapies.

The waiting period for results of BRAF tests, which did not feature in the reviewed studies, was identified in the present study as a source of consternation for some people with advanced melanoma. Awareness of melanoma as an aggressive cancer conflicted with the delay in treatment until a determination had been made. Similarly, waiting for surgery and waiting for enrolment in clinical trials caused frustration for some people in the present study. Melanoma patients' perceptions of clinical trials and perceptions of chemical treatments did not feature in the existing literature. The present study found that some people who underwent chemical therapies for melanoma were uncertain about symptoms of side effects, despite having received information about what to look for. Further, some people were hesitant to discuss side effects with the clinic staff because it might cause delays or stop treatment. The study also found that some people who had undergone chemical therapies had unclear expectations of the outcomes.

### **Contribution to what is known overall about melanoma patient experiences**

The through-line of a need for psychosocial care that was identified in existing studies was evident on par in the present study, with a lesser focus on the functionality of follow-up services and a stronger focus on the long-term nature of the relationship between patients and their healthcare providers. In the present study, some people perceived a strong connection with their oncologists based on the longevity of association, the intimacy of the emotive circumstances in which they had come together and the roles played by oncologists in planning surveillance, preventing recurrence and heralding survival.

I propose that the review method I have undertaken makes a contribution to what is known overall about melanoma patient experience, in a methodological sense. The

meta-ethnographic analysis of existing studies that had different research interests and different ways of reporting findings resolved in a meta-narrative of patient journey that provided a base for synthesis with the content findings of the present study. This may be a way forward for qualitative evidence synthesis (Booth, Rees et al. 2010) in melanoma patient experience.

### **9.3 Contribution of the research in wider contexts**

By accounting qualitatively for the patient's longitudinal point of view, this study makes a contribution in content and structure to the efforts of patient-centred policy to focus on quality of patient journey as an outcome of healthcare. As noted, patients experience healthcare not as healthcare practitioners see it—in micro domains—but as a transitionary movement through multiple settings involving numerous relationships with strangers who may or may not become long-term acquaintances. Yet in my review of the literature on patient experience in melanoma care, there was just one study that emplotted<sup>23</sup> its findings on care experiences as a longitudinal patient journey. This situation in the literature reflects the enactment and evaluation of care in disassociated 'sovereign states' of healthcare systems. Because of this disconnectedness, qualitative research on patient experience is often conducted in silos, specific to events, institutions, or particular phases of disease and disease management. Investigating patients' care experiences in 'scenes' has worth in relation to local performances of patient-centred care, however the enactment of system-wide patient-centred care may be undermined by inattention to a meta-level of patient experience. This study attends to that gap.

The research also contributes to the conceptual thinking about the identity of patienthood as it pertains to the goals of patient-centred care. In a cross-disciplinary perceptive, parallels may be drawn between the identity transformation of the central character in the archetypal narrative identified in Chapter 2, and the identity transformation that patient-centred care is setting about to achieve (Charles-Jones, Latimer et al. 2003, May, Eton et al. 2014). As noted in Chapter 1, the goal of patient-centred care is to redefine the identity of patienthood from passive to proactive. The 'inner' journey of the patient as he or she learns to take on healthcare autonomy and to reframe relationships with individual providers as a co-share arrangement (May, Eton et al. 2014) is that of the literary protagonist who learns new skills and a new world view through the challenges he or she undergoes. Thus the political narrative of patient-centred care aligns with the archetypal literary narrative of personal journey and

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<sup>23</sup> In contrast to generalised references to global or continuing themes.

transformation and affiliates the identity of patient with the idea of patient-as-protagonist, which I explored in Chapters 5 and 8.

### **Contribution to the new era of personalised care**

The meta-narrative views of patient journey introduced by this thesis are especially affiliated to the incoming era of personalised care. Advancing technology in medicine and in information management is directing us beyond the paradigm of treating people in response to disease symptoms and body-part ailments into an approach based on pre-symptom health management, the principles of systems biology and a concern with longitudinal human/environment interactivity. This vision of healthcare proposes a makeover of the deep structures of healthcare (Westbrook, Braithwaite et al. 2007) so that the enterprise of healthcare delivery can be patient-centric and networked. It will be significant to understand the outset-to-outcome patient journey because treatment pathways will widen and become more complex as medicine looks beyond stratification of symptoms (Loscalzo and Barabasi 2011) to a conception that “the human body functions as a network of interconnected tissues and biological processes and seldom does a single organ or system fail in isolation” (Nicholson, Darzi et al. 2016).

## **9.4 Conclusions**

From the lived and written narratives of healthcare experience of the study populations, I constituted my own narratives about the research, which I presented as five papers. These narratives about meta-narratives constituted the work of my thesis.

### **Limitations**

In the three full-time years of this PhD, I have completed the work that I set out to do, and found that it fulfilled its promise of being fascinating and also challenging. Yet there are limitations on the achievements of the study. There are limitations, for example, on the ethnographic work one person can accomplish in the oncology and chemo clinics that host the life-and-death drama of metastatic melanoma. My goal was to realise whatever depth of ethnographic endeavour could be achieved in the time I had with participants. While I remain excited by the wealth of opportunities for discerning narrative ethnographers now that the Internet facilitates so much self-talk, there are limits also on how many autobiographical written accounts one person can code and analyse—and iteratively code and analyse. Another limitation is identifiable in the concept of thesis by publication. This mode of delivering a thesis offered the advantage of having completed journal articles, however the data for multiple articles was derived from two studies, creating the likelihood of repetition of information about melanoma,

about methods of data collection and analysis, and about the cross-disciplinary precepts that inform the study. Finally, this study might have been designed and conducted quite differently in the hands of another researcher. Establishing methodological foundations for research that broaches both social science and narratology, and utilising relevant, well-established modes of inquiry in different ways is a tremendously interpretive endeavour. The model that most suited my capacities and skills was the exploration of melanoma patients' experiences of care through cross-disciplinary modes of narrative inquiry focused on the emplotment of patient journey.

### **Future research**

There is an opportunity in this idea of emplotted patient journey to redirect the perspective and investigate, for example, the experiences of healthcare providers in working with patients. The emplotted narrative arc of a physician as protagonist of her or his own story—which is in contrast with physician as protagonist of the patient's story—would facilitate an understanding of the phases of burden that occur over the period of a particular relationship with a melanoma patient or over a period in professional life. The scope of emplotment as a heuristic is such that it enables both the 'inner' and 'outer' journey of a person to be made visible. Since it was beyond possibility in this study to investigate the emplotment of a patient's personal identity transformation in response to experiences of care, in the sense of a psychological or existential development, there is an opportunity for future research. I touch on this in Chapter 7, in which a plot analysis of melanoma narratives identified the thread of 'inner' journey that is sewn into these stories and is stitched up most efficiently in the use of an epilogue. It is here especially that people with melanoma write the lessons learned, the wisdom gained and the lifeworld meaning that has come about from their experiences of illness and patienthood.

### **Final remarks**

The "abiding concern" (Van Manen 1990:31) of this thesis has been to source data that yield rich descriptions of patient journey, and to reinforce and expose the experience of being a melanoma patient. What I know about the melanoma patient journey now is that the road to melanoma diagnosis is complex and dislocating because patients don't always recognise or act on their symptoms, and doctors don't always recognise or act on patients' symptoms of melanoma. It can take weeks for test results from biopsies to come back and the stress of the wait can be intense. Receiving a diagnosis of melanoma can have a powerful emotional impact, and people can miss hearing critical information about their diagnosis and treatment options as they reel from the news. Surgery can take

time to organise, and the arduous, longer-than-predicted recovery from melanoma surgery is not always acknowledged by clinicians and healthcare services. Surgery can result in disfiguring scars, lymphoedema and lack of mobility that creates chronic needs for care and impacts sense of identity for the rest of a person's life.

Current chemical treatments have fewer side effects than previous medications, but they can still have challenging consequences. Clinical trials can be hard to find, difficult to enrol in and ineffective. Symptoms of recurrence may be difficult to recognise—they may come up as a lump, a bruise, hip pain, headaches or vision issues. People with advanced melanoma are not likely to live beyond six months from diagnosis. Those with less advanced melanoma whose treatment has been effective still face a fear of recurrence that is pervasive, and have expectations that psychosocial care will be managed in regular clinical reviews for the rest of their lives.

The study I completed was grounded in the empirical and theoretical knowledge delivered by the social scientists, physicians, narratologists, literary analysts and sociologists whose work I have referenced—those scholars and medical practitioners who are focused on patients' experiences in the biomedical enactment of healthcare and those who take an interest in narrative as a system of understanding and representing illness and patient experience. The work on relationships between narrative, medicine and health has been building over the last fifty years, since personal stories began to have 'currency' as evidence, and narrative texts of all kinds became legitimate resources for investigating what it means to be ill and to be a patient. I have referenced many people whose points of view have been so expertly constructed and whose studies have been so convincing as to shift paradigms in thinking about narrative inquiry into patient experience.

The thesis builds on those 'shoulders' to establish a set of narrative methods by which to investigate melanoma patient experience as a phenomenon. A conclusion of the study is that the use of narratological precepts and literary heuristics, most especially the emplotment of patients' experiences to comprehend meta-narratives of patient journey, is an innovative approach to qualitative research on patient experience. It can highlight patients' perspectives on the trajectories they make through the system and expose the challenges that patients feel they face as they move through those trajectories. Moreover narrative emplotment captures patients' experiences as they progress over time, and as they compound throughout the patient journey, contributing knowledge of the long-term impact of healthcare experiences on people's capacity to understand, and manage, their own health. As healthcare shifts into new paradigms of care delivery, driven by

economic imperative and framed by new technologies, the patient journey, as the patient sees it, is becoming focal. The contribution of this thesis is the systematic and principled application of narrative precepts to the investigation of the patients' experiences, providing clinicians, healthcare administrators and policy-makers with an approach to organisational and dyadic patient-centred care (Coulter and Locock 2014) that privileges the patient perspective.

In view of the complex trajectories that people with melanoma make in often life-threatening circumstances, the growing incidence of the disease, the resource burdens the disease imposes on healthcare systems and the dearth of patients' perspective in research on melanoma care, this thesis above all makes the contribution of knowledge about what it is to be a melanoma patient and to make a patient journey.



## APPENDICES

**Appendix A:** Research Study Participant Information Sheet and Consent Form—Patient journeys

**Appendix B:** South Eastern Sydney Local Health District Human Research Ethics Committee approval (HREC 15/078) for ‘Patient journeys as lived narratives and the relevance of the hero journey’.

**Appendix C:** Macquarie University Human Research Ethics Committee approval (HREC 5201600665) for ‘The melanoma patient journey told in online narratives’.

Appendix A-C of this thesis have been removed as they may contain sensitive/confidential content

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