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# Patients as story-tellers of healthcare journeys

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## 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 story-telling 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 in and moving through the healthcare system.

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 interdisciplinary fields of *narrative medicine* and *health humanities*, which look to the structure of fictional texts, among other forms of creative expression<sup>1–2</sup> to understand experiences of patients,<sup>3</sup> and to develop narrative competence in experiential story-telling and story-listening.<sup>4</sup>

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.<sup>5–10</sup> 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 policymakers, as the importance of *listening* well to stories of illness.<sup>11</sup>

How patients narratively perceive and convey their experiences varies with narrative capability and propensity,<sup>3</sup> and also with the trauma of illness and treatment; the 'wounded story-teller'<sup>8</sup> may struggle with the narrative confidence to speak of sickness and patienthood. A patient-journey story-telling model may be an apt tool in facilitating patients to narrate their experiences.

In the narrative arc of the fictional hero journey,<sup>12–14</sup> 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

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## Review essay

**Table 1** This table sets out an appropriated structure from Campbell's three-stage model, mapped to a potential analogy with the patient-journey experience

Scene	Quest narrative model	Patient-journey model
<i>First stage</i> Interruption of Ordinary World and crossing the threshold into the Special World	The central character is introduced in the context of an inciting incident that is pulling him or her from the Ordinary World and compelling him or her towards a Special World. The character is forced to face change.	<i>The story is told of a person experiencing injury or illness, or noticing a symptom that compels him or her to seek medical expertise. The story describes entry into patienthood, and the new setting for the story becomes the healthcare system.</i>
<i>Second stage</i> The Road of Trials and Obstacles	The central character is tested with new challenges and begins to sort out the rules of the Special World. The character is faced with personally confronting situations and goes into the 'belly of the whale', facing his or her greatest fear.	<i>The patient describes the events and interactions of treatment, portraying perceptions of the idiosyncrasies of different healthcare settings and stakeholders and the personal impact of the experiences.</i>
<i>Third stage</i> The road back to New Normal	The character realises that the critical period of the journey is over and the Special World must be left behind. The journey must be made to the New Normal—life lived with a revised sense of self that incorporates the experiences of the journey.	<i>The patient's story comes to a close as the medical trajectory, or phase of the medical trajectory, is completed. The patient contemplates a new conception of normal, incorporating changes in lifestyle, ongoing health issues or perhaps even life ending.</i>

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, shape-shifters 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:

1. 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;
2. Encounters with healthcare services during the critical episodes of treatment;
3. Experiences of follow-up care services and ongoing illness management.

In the patient's story-telling 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.

**Table 2** The hero journey model identifies archetypal stakeholders that recur in hero journey stories

Archetype	Quest narrative	Patient-journey model
Central character/hero	Central figures—the protagonist of their own story.	Patients as both story-teller and protagonist.
Herald	Person or event that compels the central character to cross over the threshold into the Special World.	Symptoms, self, other, General Practitioner.
Mentors	Advice-givers, or own guiding principles.	Medical professionals, other clinicians, others with similar illness experiences.
Shadows	People or events that act as villains and enemies, or perhaps the enemy within.	Administrative obstacles, unclear, clinical options, personal fears.
Threshold guardians	Forces that stand in the way at critical points, including professional gatekeepers, or own fears and doubts.	Medical receptionists, overdue test results, personal concerns.
Shape-shifters	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.
Tricksters	Mischief-makers, or own mischievous subconscious.	False diagnoses, medication that does not work, or that causes allergic reactions.
Allies	Support characters and helpful events that facilitate the protagonist through the journey.	Medical professionals, administrative and facility staff.

This table maps out a potential correlation with stakeholders in the patient-journey experience.

## 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 story-telling. 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,<sup>8 15 16</sup> others may not.

The twist, however, is that regardless of whether the patient-as-protagonist is a heroic figure, the patient-as-story-teller achieves a special feat by being the 'voice of the experience and the voice of the expert'.<sup>17</sup> Patients as story-tellers bring the boon of experiential knowledge to their audience community of clinicians, policymakers and other patients.<sup>11</sup> 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<sup>18 19</sup> and safety<sup>20 21</sup> in healthcare systems. Accounts of patient experience are considered integral to programmes that enhance clinical competence,<sup>22 23</sup> and that endeavour to engage people with their own health.<sup>24 25</sup> Programmes 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.<sup>26</sup> This is the value of patients' stories.<sup>3 11 27 28</sup>

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.

**Contributors** KL initiated the paper, did the first draft and reviewed the literature. JB contributed to multiple drafts, added appropriate ideas and edited the final version. Both authors agree with the final version.

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## REFERENCES

- Hurwitz B, Charon R. A narrative future for health care. *Lancet* 2013;381:1886–7.
- Jones T, Wear D, Friedman L, et al. *Health humanities reader*. New Brunswick, NJ: Rutgers University Press, 2014.
- Woods A. Beyond the wounded storyteller: rethinking narrativity, illness and embodied self-experience. In: Carel H, Cooper H, eds. *Health, illness and disease: philosophical essays*. Durham, UK: Acumen, 2014:113–28.
- Charon R. At the membranes of care: stories in narrative medicine. *Acad Med* 2012;87:342–7.
- Cooper I. A conversation with John Green & Ilene Cooper. Booklist. 1 Jan 2012. <http://go.galegroup.com.simsrad.net.ocs.mq.edu.au/ps/i.do?id=GALE%7CA279137571&v=2.1&u=macquarie&it=r&p=EAIM&sw=w&asid=4e05a32f2e8b885435d9412cc95a0d11>
- Hutchinson T. Illness and the hero's journey: still ourselves and more? *CMAJ* 2000;162:1597.
- Ramsden P. The patient's heroic journey. *BJHCM* 2010;16:328–31.
- Frank A. *The wounded storyteller: body, illness, and ethics*. 2nd edn. Chicago, IL: University of Chicago Press, 2013.
- Jessop E. The quest for diagnosis: a narrative analysis of patient journeys. *RARE J* 2014;1:108–15.
- Smith B. Disabled bodies and storied selves: an example of qualitative research and narrative inquiry. *EUJAPA* 2008;1:23–34.
- Charon R. What to do with stories: the sciences of narrative medicine. *Can Fam Physician* 2007;53:1265–7.
- Campbell J. *The hero with a thousand faces*. Novato, CA: New World Library, 1949.
- Vogler C. *The writer's journey: mythic structure for writers*. Studio City, CA: Michael Wiese Productions, 1998.
- Booker C. *The seven basic plots: why we tell stories*. London, UK: Bloomsbury Academic, 2004.
- Kleinman A. *The illness narratives: suffering, healing, and the human condition*. New York: Basic Books, 1988.
- Carel H, Cooper R. *Health, illness and disease: philosophical essays*. Durham, UK: Taylor & Francis, 2014.
- Gabriel Y. *The voice of experience and the voice of the expert—can they speak to each other? Narrative research in health and illness*. Hoboken, NJ: Blackwell Publishing Ltd, 2008:168–86.
- Coulter A. Understanding the experience of illness and treatment. In: Zeibland S, Coulter A, Calabrese J, et al., eds. *Understanding and using health experiences: improving patient care*. Oxford, UK: Oxford Scholarship Online, 2013:6–15.
- Sondergaard EG, Grøne BH, Wulff CN, et al. A survey of cancer patients' unmet information and coordination needs in handovers—a cross-sectional study. *BMC Res Notes* 2013;6:378–8.
- Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013;3:e001570.
- Churchill N. Taking care of your experience [Internet]. NHS England (updated 30 Jan 2015; cited 18 Nov 2015). <https://www.england.nhs.uk/2015/01/30/neil-churchill/>
- Jha V, Quinton ND, Bekker HL, et al. What educators and students really think about using patients as teachers in medical education: a qualitative study. *Med Educ* 2009;43:449–56.
- Coulter A. *Engaging patients in healthcare*. Berkshire, UK: McGraw-Hill Education, 2011:65–7.
- Greenhalgh T. Story gathering: collecting and analysing spontaneously-shared stories as research data. In: Zeibland S, Coulter A, Calabrese J, et al., eds. *Understanding and using health experiences: improving patient care*. Oxford, UK: Oxford Scholarship Online, 2013.
- Baron S. Evaluating the patient journey approach to ensure health care is centred on patients. *Nurs Times* 2009;105:20–3.
- Schembri S. Experiencing health care service quality: through patients' eyes. *Aust Health Rev* 2015;39:109–16.
- Greenhalgh T, Hurwitz B. Narrative based medicine: why study narrative? *BMJ* 1999;318:48–50.
- Hawkins J, Lindsay E. We listen but do we hear? The importance of patient stories. *Br J Community Nurs* 2006;11:S6–14.



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