

## Expanding Narrative Medicine: Four Notes

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### Résumé de l'article

Envisager les futurs possibles de la bioéthique nous invite à interroger nos théories et méthodes existantes. Ce texte se concentre sur les futurs de la médecine narrative, en proposant quatre notes pour une pratique élargie. Plus précisément, je soutiens que les travaux futurs en médecine narrative peuvent bénéficier d'une interrogation sur les champs d'application, les archives et les méthodologies de la médecine narrative, ainsi que d'un investissement dans des supports matériels.

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TÉMOIGNAGE / PERSPECTIVE

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C Dalrymple-Fraser<sup>a</sup>

### Résumé

Envisager les futurs possibles de la bioéthique nous invite à interroger nos théories et méthodes existantes. Ce texte se concentre sur les futurs de la médecine narrative, en proposant quatre notes pour une pratique élargie. Plus précisément, je soutiens que les travaux futurs en médecine narrative peuvent bénéficier d'une interrogation sur les champs d'application, les archives et les méthodologies de la médecine narrative, ainsi que d'un investissement dans des supports matériels.

### Mots-clés

médecine narrative, narration, santé publique, récits autochtones, bioéthique

### Abstract

Considering the possible futures of bioethics invites us to interrogate our existing theories and methods. This text focuses on futures for narrative medicine, offering four notes for an expanded practice. Specifically, I argue that future work in narrative medicine can further benefit from interrogating the scopes, archives, and methodologies of narrative medicine, and investing in material supports.

### Keywords

narrative medicine, narrative, public health, Indigenous storywork, bioethics

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## INTRODUCTION

Reflecting on the possible futures of bioethics invites us to interrogate our existing theories and methods. This text focuses on futures for narrative medicine, offering four notes for an expanded practice. Specifically, I argue that future work in narrative medicine can further benefit from interrogating the scopes, archives, and methodologies of narrative medicine, and investing in material supports.

### 1. NARRATIVE MEDICINE

Put broadly, narrative medicine argues that engaging with stories is important for health and healthcare. For scope, this text focuses on the traditions of narrative medicine developed in the “Columbia” school of narrative medicine, as expressed through landmark works like Rita Charon’s *Narrative Medicine* and the edited collection *The Principles and Practice of Narrative Medicine* (1-2). Nonetheless, my remarks here also apply to other narrative approaches.

The Columbia school of narrative medicine offers that building “narrative competencies” for engaging patient narratives can promote better and more equitable care, such as by “increasing the accuracy and scope of clinicians’ knowledge of their patients and deepening the therapeutic partnerships they are able to form” (2, p.1). Inviting patients to share more open-ended stories can reveal clinically important information that might be omitted in a standard clinical interview, such as possible behaviours, exposures, or symptoms that may otherwise go unreported. These stories can also add layers of meaning to the patient encounter, by helping clinicians to understand “what their patients go through [and] to attain that illuminated grasp of another’s experience” that cannot be captured by mere clinical descriptions of illness (1, p.11).

Meanwhile, authors argue the stories we tell are more fundamentally part of who we are; engaging with patient narratives can thus be a way of more directly engaging with patients as people, and not merely as collections of symptoms to be assessed and redressed. For these reasons, Charon and others argue that stories can thus help build clinical relationships of trust, care, and bridge gaps in understanding, beyond stories’ clinical utility (1-2).

Importantly, the Columbia school emphasizes narrative’s potential contributions to developing more equitable care (2). Charon offers that the close reading skills involved in narrative competencies, including centring intersubjectivity and bearing witness to suffering, positions clinicians to “respond skillfully to accounts of trauma and injustice, equipping the listener with the resource of nonjudgmental attention” (2, p.176). While narrative medicine may not uniquely position clinicians to identify and respond to injustices, it nonetheless positions itself as one guide toward just care.

Finally, these clinical benefits of narrative can also translate to research benefits. Where large population studies can conceal the grain of individual differences, Charon suggests that narratives as evidence can reveal the pitted landscape and complexities of illness experiences, just as individual patient stories can invite us into experiences that are occluded by clinical descriptions of illness (1). Indeed, outside of narrative medicine, narrative research methods are well established if uncommon (4-5,17).

In brief, narrative medicine argues that the skills and virtues developed through close reading of stories can benefit patient care and research, and I largely agree. Nonetheless, I argue that there is room and reason to push further.

## 2. THE SCOPE OF NARRATIVE MEDICINE

Literature on narrative medicine primarily focuses on clinical applications, engaging with individual patients within health institutions. While early proponents indicated that narrative can skillfully operate at “all levels of health care, from individual clinical encounters to global public health efforts” (1, p.229), relatively little attention has been given to narrative medicine beyond the clinic (3-4). Still, many of the methods and benefits of narrative medicine that support individual-level care can plausibly scale to community-level health as well, and these are directions worth pursuing further.

Charon argues that engaging patient narratives can improve trust and caring relations with patients (1). These same benefits can plausibly apply to group narratives, and can support community-level trust and health initiatives. For example, we might engage with a Black patient’s vaccine hesitance or refusal through their individual narrative history. But identifying broader patterns of hesitancy and resistance in Black communities will demand that we attend to community-level narratives around shared experiences of medical racism, abuse, experimentation, and neglect – collective stories and patterns that can be obscured at the individual level. Where narrative medicine seeks to build trust through careful, extensive, and engaged listening, the same can be sought through community narratives. Importantly, community-level narrative medicine could reach and benefit people less likely to access institutional spaces, such as those experiencing financial and geographical barriers to healthcare, or histories of medical abuse, trauma, or neglect. If we focus only on individual stories in clinical encounters, we will necessarily miss the stories of those who do not arrive to the clinic.

Others argue that attending to individual stories can mitigate harmful “master narratives,” that is, dominant social narratives that uphold harmful stereotypes (2). These harmful narratives might include the claims that disabled people are unproductive drains on social resources and in medical need of “fixing,” for example. Engaging with patient stories can help resist these dominant narratives through counterstories, narratives that alter “others’ perception of an oppressed group as well as the self-perceptions of those within the group” (2, p.98).

Engaging collective narratives at broader community levels can help disrupt these harmful dominant narratives further upstream. That is, while identifying individual exemptions to general narratives is valuable, so is interrogating the heuristic value of those narratives themselves and replacing them with more representative stories. Where narrative medicine currently focuses on the former, we can also attend more to the latter. Still, we must be cautious not to resolve into abstracted assessments of narrative trends within a population, which risks obscuring differences and replacing one dominant narrative with another.

Initial work on translating narrative medicine beyond institutional settings does exist (3-4), and other uses of narrative regularly appear in community-level health even if they do not directly engage narrative medicine scholarship. For example, stories are often used as evidence for public policy and legislation, such as appeals to physician and patient experiences in consultations on expanding eligibility for Medical Assistance in Dying. Finally, community-engaged research also increasingly centres stories through oral and written narratives, photovoice, and archival research (4-5). Extending narrative medicine beyond the clinic can be better supported by engaging these existing projects.

## 3. BROADENING NARRATIVE ARCHIVES

Stories can come in many different forms. A more robust narrative medicine must continue to interrogate what is covered under the umbrella of “narrative.” Momentum already exists in this direction, with scholars and practitioners analyzing not only patient narratives, fiction, and illness biographies, but also poetry, graphic novels, film, music, painting, and more (2). These existing moves to broaden our account of narratives are important for at least two reasons. First, not everybody communicates in the same mediums, and this is especially true in healthcare where patients arrive with a variety of disabilities and illnesses that can impact fluent oral and written communication. Second, a broader account of narrative can help resist “narratocracies” that privilege certain exclusionary accounts of legibility or sense-making (6). The future of narrative medicine will benefit from keeping open the question of what counts as “narrative.”

However, beyond focusing on different forms of stories, it is important to interrogate where and how we access those stories. What archives are we building and using? While much of narrative medicine’s attention is focused on patient narratives, many of the stories which are most critical of health and healthcare come from those less able or willing to access institutional spaces – from those who are less likely to appear as patients or to share their stories.

For example, transgender patients regularly report being denied care, receiving inappropriate care, or even being harassed, and avoid accessing healthcare or withhold their disclosures in those spaces as a result (7-8). Exempting a few dedicated venues like the journal *Narrative Inquiry in Bioethics*, these stories are less likely to already appear in healthcare institutions, conferences, journals, or other mainstream academic and professional health archives. Instead, they appear in poetry slams, in hand-distributed zines, in online communities and hashtags, and other spaces not yet attended in narrative medicine literature, when they are told at all. A more just narrative medicine must broaden the archive to include these less accessed

or accessible stories, and in general focus on those stories which often appear absent, silent, or obscured in mainstream narrative spaces.

Accordingly, a more just narrative medicine will attend further not only to what we count as a narrative, but where and how we access narratives. A narrative medicine that centres the most readily available stories will reflect only a fraction of the stories relevant to health and healthcare, and centre those that already have the relative privilege to be safely told and listened to. As Sayantani DasGupta cautions, a narrative medicine that does not attend to power and privilege risks upholding and reproducing “the selfsame hierarchical, oppressive power dynamics [...] that the field is designed to address” (2, p.137).

The future of narrative medicine requires us to grapple with questions like: What stories have been excluded or occluded by our primary archives and theories of narrative? How could we ethically visit and engage with stories told through other means, like poetry slams, zines, blogs, potlatches, or drag shows? How can we build more just narrative practices and archives, while protecting the secrecy and silences of stories that are not ours to share, or that are unsafe to tell? Existing work into epistemic oppression in healthcare, participatory action research, and Indigenous storywork protocols may provide supporting frameworks for this work.

#### 4. ENGAGING EXISTING NARRATIVE METHODOLOGIES

When considering what stories have been excluded, we must also attend to excluded narrative methods. The relationships between narrative, health, and healthcare have long been theorized and practiced across the globe, and what is often called the “narrative turn” in medicine and bioethics is perhaps more appropriately a “return” to narrative. In what we currently call Canada, for example, there are many rich traditions of Indigenous storywork that are largely unaddressed by narrative medicine and by healthcare more generally (12-17). Consider two immediate consequences of this exclusion.

First, if narrative medicine supports quality healthcare – particularly for patients who have not typically had their stories heard – then a narrative medicine that excludes Indigenous peoples, stories, and methodologies risks upholding existing disparities in quality health and healthcare. The justice that narrative medicine strives for requires listening to patients on their own terms, and this can be impeded by inadequate engagement with the traditions and methods that inform those terms (2,6).

Second, more generally, excluding existing narrative methods impedes further inquiry and theorizing, and risks “reinventing the wheel.” For example, I have argued that principles of narrative medicine could be expanded to community-level health. This expansion would require engaging issues of collective narratives and group authorship, issues which less frequently arise in clinical settings with individual patients, and which may require developing new resources and methods. However, many storywork traditions have established communal storytelling methods and ethics, which often centre relationality and narrative stewardship, and which could guide attempts to broaden narrative medicine (12-17). Still, these traditions are not engaged by narrative medicine scholarship, despite narrative medicine’s commitment to representation and just healthcare. If we wish to build a more just narrative medicine, we will need to attend to excluded methods and traditions.

However, non-Indigenous people must exercise caution in how we address these exclusions and how we access and engage stories and methods that are not our own. Inclusion for inclusion’s sake is not a virtue, and access to stories can be a source of harm. For example, consider the governmental debates over which organizations “own” – and can thus archive or destroy – the stories of residential school survivors extracted during the Indian Residential Schools Settlement Agreement assessment processes. Meanwhile, Indigenous stories and traditions continue to be attacked through land dispossession and displacement; lost alongside the patients ignored to death in hospitals; muffled by the destruction of Indigenous languages; and stolen through ongoing legacies of residential schooling, forced adoption, and missing and murdered Indigenous women, girls, and Two-Spirit people. It is no secret that these forms of violence have often involved Canadian healthcare institutions and practitioners (9-11). Focusing on building access to peoples and stories, without addressing the harms that have historically accompanied desires for access, risks perpetuating these injustices.

Overall, uncritical efforts at engaging traditions and knowledges can reproduce patterns of narrative extraction, exploitation, appropriation, and harm (6). Nonetheless, refusing to engage at all can uphold existing disparities and inadequately informed narrative methods. While I focus on Indigenous storywork, these cautions apply more generally when engaging communities and methods other than our own. Minimally, we should ensure that our learning follows the leadership, traditions, and protocols of communities, and that we address the upstream determinants of these injustices (3-8,12-17). For those researching or practicing narrative medicine in Canada, introductions to some types of Indigenous storywork are offered by Jo-ann Archibald Q’um Q’uim, Daniel Heath Justice, Margaret Kovach, Neal McLeod, Leanne Betasamosake Simpson, and Shawn Wilson (12-17).

#### 5. INVESTING IN NARRATIVE

Ultimately, engaging narratives is resource intensive, even in the narrower understanding of narrative medicine within clinical and research contexts. In clinical settings, increasingly strained staffing ratios yield limited time to listen to and engage with patients and their stories, let alone to record those stories in charts as some scholars suggest (1). This time pressure can be exacerbated in institutions that enforce strict time-to-discharge standards as a strategy for managing staffing ratios, and for precariously employed clinicians who feel pressured to follow institutional guidelines for reasons of job security.

In research settings, narrative and qualitative analyses are also time intensive, particularly when it comes to transcribing, coding, and triangulating stories. Researchers undertaking community-engaged research practices, participatory action research, or other forms of collaborative design with historically excluded communities may also tend to require more time than research projects that require fewer consultations, in addition to longer possible ethics approval timelines (5). These time costs can often translate into financial costs that impose further barriers for researchers working with limited and often insufficient funding. Finally, these costs can also make narrative medicine seem professionally risky for junior scholars expected to meet research output goals for their degree, tenure, or promotion. These material and institutional barriers may contribute to the relatively low prevalence of narrative and qualitative research in medicine (18), and may make narrative medicine seem like an ideal rather than a practical approach in current clinical contexts.

Prospectively, some of these costs might be defrayed by advances in machine learning and artificial intelligence. For example, improved speech recognition tools can facilitate transcribing patient stories in clinical or research contexts. Machine learning could also enrich existing coding technologies and facilitate inter-rater reliability in research. While these technologies are still emerging and raise their own concerns of bias, transparency, privacy, and data ownership, they represent a productive area for future inquiry. Nonetheless, many of these issues are more structural in nature.

Accordingly, the future directions for narrative medicine described here will require investing in narrative medicine with time, funding, and professional accommodations. In addition to supporting projects like *Narrative Inquiry in Bioethics*, this may include structural changes such as increased funding to address inadequate staffing and wages; supporting research-responsive tenure timelines and requirements; increasing access to qualitative research training for students and researchers; and developing grants and supports for community-driven anthologies and other narrative projects.

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