Editorial Commentary | Communication in Palliative Medicine and Palliative Care

Storytelling & the unspeakable: narratives in/about palliative care

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Keywords: Narrative medicine (NM); storytelling; medical humanities (MH); illness narratives; interdisciplinarity

Submitted Mar 01, 2023. Accepted for publication Dec 19, 2023. Published online Feb 21, 2024.

doi: 10.21037/apm-23-252

View this article at: https://dx.doi.org/10.21037/apm-23-252

Introduction

By telling stories we connect—with ourselves and one another. Personal experiences with illness often act as a catalyst for storytelling as these enable us to express our suffering to other people in the hope that they hear, honor, and validate our experience. Before becoming "*the subject of medical scrutiny, [the patient] is, at first, simply a storyteller, a narrator of suffering*" (1). Spoken and written narratives function differently on many levels but they do have one thing in common: narrative medicine (NM) occupies itself with all of them.

NM can be viewed as an interdisciplinary and patient-oriented approach to clinical practice that focuses on listening carefully to the stories told by patients. Closely related to medical humanities (MH), a field of research at the interface of medicine and the humanities, NM offers a more methodological approach to changing the practice of medicine (2). This includes following the patient's narrative thread, being aware of the unspoken subtexts, and being open to storylines that deviate from the diagnostic-centered stories of illness. This is to narrow the gap between patients and health care professionals[1] by supporting the latter in developing the capacity for attention, representation, and affiliation—skills that Rita Charon describes as the three movements of NM (3). Among others, the overarching goal is to provide a more humane care that makes the patient the center of attention without neglecting the individual stories of caregivers. Furthermore, patients' stories are considered a valuable source of information when it comes to gathering data in the process of diagnosis and treatment (4).

Although NM is an intellectual and clinical practice that is open to a wide range of disciplines (among them social studies, anthropology, gender studies, and the arts), literary studies offer the theoretical foundation—mainly close reading—for teaching narrative competence, the ability that constitutes the foundation of skillful listening (3). This editorial commentary briefly reflects on the particular role of storytelling in palliative care and offers a more nuanced approach to different narratives from a literary studies point of view within the already interdisciplinary field of NM. It differentiates between spoken and written narratives—clinical communication versus reading literary texts to teach narrative competence—in order to take a closer look at the educational value of literature in medicine. NM can add useful perspectives on daily clinical interactions and give care workers the opportunity for self-reflection during all stages of their career. Situations where the need to take a closer look on how stories work occur between physicians and patients, between colleagues in the realm of medicine, and regarding the individual medical professional's self-perception. They can also concern the relationship between care givers and public expectations: how do we talk about certain illnesses and how to take action against stigmatization?

[1] NM and MH include various professional groups of health care workers (doctors, nurses, therapists, social workers).

Storytelling in palliative care

Toni Morrison's Nobel Prize lecture from 1993 is often cited when it comes to the potentials of a narrative approach to palliative care. "*We die. That may be the meaning of life. But we do language. That may be the measure of our lives.*" (5). Narrating life and transforming thoughts into words seems to be mandatory in a medical field that specializes in offering a variety of forms of care to improve the quality of life for seriously ill patients who are eventually confronted with the fact that their disease may not be curable. It is an active endeavor which calls for specific communicative skills and encouragement, nothing that simply happens. The need for both patients and medical professionals to voice their stories and feel heard in order to more fully understand their experiences can be seen as a connecting element. However, within the clinical relationship receivers and providers of care are divided into two groups: Those who are sick and immediately experiencing illness and those who are professionally obligated to deliver care to them. The medical setting inherently puts barriers between patients and healthcare-professionals—among others, the relation to mortality, the contexts of illness, beliefs about disease causality, and the emotions of shame, blame, and fear have been named (3).

Generally speaking, palliative care is associated with a disease specific approach dealing primarily with fatal illnesses. The more accurate definition includes a broader perspective that also focuses on chronic illnesses governed by the principle of applying palliative measures as early as possible and often alongside curative treatment. Conveying difficult messages is among the greatest challenges for any doctor, but when it comes to chronic and incurable diseases keeping a balance between honesty and hope is perceived as especially challenging. The complex interaction between medical professionals and patients in palliative care thus requires specific consideration about what, when, and how to say something and in addition an awareness of non-verbal cues. Medical communication is in itself a highly specialized language. From the very beginning, students learn to follow a certain script when talking to patients, a script they have to adapt consistently throughout their careers. Besides, empathetic communication is a clinical skill that improves the therapeutic relationship and impacts patients in positives ways. Nevertheless it is important to be aware of the potential dangers of empathy, as Jane Macnaughton has noted: "*Any mirroring of feeling will always differ quantitatively and qualitatively from that patient's experience*." (6). The aim is to always practice open communication while preserving the dignity and autonomy of patients (4) and assessing the whole person as part of care—not just their diagnosis. The definition of empathy—especially in the clinical context—could thus be reworded as the ability "*to stand in another's shoes without actually leaving your own shoes*" (7). Although this explanation is certainly redundant for the intended readership of a journal of palliative medicine, it is still important to highlight specific requirements for clinical communication because many scholars conducting research in the field of NM do not have a medical background. This means that different outsider perspectives must be taken into account—on both sides of interdisciplinary research.

Whereas literary or other humanities-based scholars usually do have little experience with the professional clinical discourse, medical doctors are usually not familiar with the different theories and methods of narratology (the study of narrative structure) or scientifically grounded text analysis that are fundamental to literary studies. While there certainly are multi-professional exceptions, Rita Charon probably being one of the most famous, the majority of scholars in the area of NM have very specialized backgrounds. This demonstrates how urgent yet difficult practiced inter- and transdisciplinarity really are. The common goal has to be to shed further light on concrete examples that show how NM can be applied to palliative care while bearing in mind that there are different approaches to and participating fields of research within NM in the first place.

From a literary scholar's perspective, the first thing that becomes evident is that there are various agents involved when it comes to storytelling in palliative care. In the face of suffering and serious illnesses, stories can build bridges between patients, relatives, and caregivers without closing the professional gap. In situations where the ubiquitous end of life becomes palpable instead of hypothetical, it can lead to a shift in storytelling that concerns the person affected directly and everybody around them. For many it becomes vital to recount certain incidents that happened long ago whereas the urge to soothe and reassure becomes a unifying element in interpersonal communication. While the terms story and narrative can be used similarly in a general sense, they differ in meaning when looked at specifically. Essentially, a story is what happens in a narrative, while a narrative is how a story is told. Another overlapping term is plot often used interchangeably with story. The plot not only explains what happens but also adds causality—a series

of events unfolding from start to finish.

NM suggests that patients' narratives can be analyzed in similar ways as one would look at a literary text because both offer a plot, different characters, and metaphors. Although the terminological differences are not vital for this contribution, they point to an important distinction that has to be kept in mind: actively listening to patients' narratives and trying to "*recognize*, *absorb*, *interpret*, *and be moved to action by the stories of others*" (3)—the skills that Rita Charon describes as 'narrative competence'—is a quite different undertaking than reading or teaching literary texts for educational purposes. A person's life-story or the conflicting thoughts that come up when faced with a serious diagnosis cannot be neatly put between book covers nor can spoken and written accounts be compared directly (8). Immediate considerations are intuitive, often inevitable, and unstructured almost by definition. Finding words and expressing those thoughts to others—in whichever way or form—can certainly help patients to establish order and find meaning, provided that the receiver is able to listen skillfully and in an appropriate way.

Nevertheless, there should never be a demand for patients to unravel their thoughts in a specific way or at all because there is no need to make their story comprehensible for others apart from, ideally, themselves. Conversely, outliving someone also means that one has to deal with the stories that survive, while a loved one—or patient—does not. Usually there is time and space for friends and family to grieve, whereas it is expected from doctors to cope in a professional way. For medical professionals, literature can serve as an experimental field where different scenarios can be fictionally evaluated without real-life consequences. Immersing oneself in a literary text can highlight existential questions which can help readers to give meaning to everyday occurrences through reflection.

The absence of narrative

But how can we talk and write about something so ambivalent and difficult to understand as death? Isn't there something unspeakable in every conversation about the end of life? Can we even fathom the multi-facetted meanings of death without speaking about life itself? In clinical practice patients, relatives, and clinicians become storytellers who inevitably also share a meta-story through their interactions. Although NM encourages creative and reflective writing (9), most stories are exchanged in direct communication. While some patients may feel comfortable talking to doctors and nurses who are actually strangers, others may have difficulties opening up and prefer silence over words. Apart from personal preferences the patients who are not able to express themselves verbally due to their condition must not be forgotten.

In and outside the medical context death is undeniably associated with stillness and in palliative care there especially ought to be a lot of room for it. When writing about Anton P. Chekhov's death in a spa near the black forest in Germany in 1904, biographer Henri Troyat tries to describe this axiomatic absence of words and sounds decades later. It has been reported by his wife that Chekhov, seriously ill from tuberculosis, drank a glass of champagne right before passing from life to death "*with characteristic simplicity […] There were no human voices*, *no everyday sounds*." (10). This depiction, although non-fictional from a literary genre-perspective, sounds romanticized and at the same time blunt—as though comprehending the essence of what just happened could not be expressed through words. This is where the subjectivity of the reader's response comes into effect. Engaging in a literary text, readers can bring in their own assumptions and experiences about death and dying. Whereas in daily clinical practice the professional duty of doctors is to try their best to understand their patients' stories, literature allows them to interpret more freely and without the need to follow any obligations. Even a short line like this one from the biography of a famous writer could evoke memories from their own clinical practice and encourage them to reflect on the working conditions they are dealing with ('*Is the clinical department I work in ever completely void of everyday sounds?*'); or it could be met with refusal ('*As a doctor I don't think that the passing of a patient can ever be simple*.').

The boundary between life and death resembles, in a metaphorical sense, the one between fact and fiction (11). Literary texts offer the chance to witness another person's suffering, a glance into historical medical practices or simply a story that raises questions based on the interpretation of the plot. Facing his own death, Anatole Broyard wrote: "*While books have always tried to show us how to live*, *they are trying now to teach us how to die*." (12). Besides fictional texts that are suitable for NM seminars this includes narrative self-creations such as autobiographical/-pathographical and life-writing accounts. The question 'What to read in medical education?' has been discussed extensively within NM with answers ranging from "*non-medically inflicted texts*" (13)

to comprehensive selections of pathographies or stories that center around illnesses.

Experience put between book covers

Dealing with the pressure that comes with being a medical-professional is especially demanding for newly educated doctors who have yet to gain comprehensive practical expertise. Stories from experienced colleagues are important for younger professionals because they are proof that self-doubt and adaptive difficulties are part of their clinical development (4). Another valuable source of stories written from the perspective of fellow co-workers can be compiled under the umbrella term 'medical-profession writing' that includes authors like Atul Gawande, Siddhartha Mukherjee, Danielle Ofri, and Paul Kalanithi (14). They can be read as an addendum to medical textbooks that, according to Gawande in "Being Mortal", "*had almost nothing on aging or frailty or dying. How the process unfolds, how people experience the end of their lives […] the purpose of medical schooling was to teach how to save lives, not how to tend to their demise.*" (15). Kalanithi, whose double-perspective as a doctor who became a patient provides distinctive insights into the process of dying, wrote about books as his "*closest confidants, finely ground lenses providing new views of the world.*" (16). Both authors make use of intertextual references to Leo N. Tolstoy's classic short novel "The Death of Ivan Ilyich". While Kalanithi feared that he would become Tolstoy's stereotype of a doctor, "*preoccupied with empty formalism, focused on the rote treatment of disease*" (16), Gawande remembers discussing the text in a seminar on mortality and being confident that he would act differently than the fictitious doctors treating Ivan—only to be confronted with the realities of decline and mortality later in his career and sympathize with them (15).

In this sense Gawande could have been part of the reading group described in the contribution 'Giving Sorrow Words'. DasGupta *et al.* report how they read the exact same novel in an NM course at Columbia University. The students discussed why Tolstoy would announce the protagonist's death at the beginning of the novel and one interpretation was that this order of events puts the focus on the process of dying without distracting readers with curiosity about whether or not Ivan is going to die (17). Insights like these can be gained through shared subjectivity which is ideally supervised and guided by an interdisciplinary group of teachers. Discussing ethical questions on the basis of the instructed reading of a literary text that leaves room for subjective perceptions and potentially surfacing emotions can help one cope professionally with the stories shared by patients (8). The impact of reading and teaching literature in medical education or engaging in clinical reading groups is a prevalent research subject in NM. Since empirical research is not a standard practice in the humanities (especially the 'Geisteswissenschaften'), the demand for evidence-based findings can, as Anita Wohlmann points out, lead to difficulties in scholarly exchange (18). The effects of a work of art cannot be measured in the same way as those of a new drug and while medicine is primarily concerned with their effectiveness for a large number of people, dealing with a literary text is a highly subjective and even intimate endeavor. It can be seen as another way to connect with others and ourselves—through written accounts—in order to balance compassion and resilience in a professional manner and according to clinical requirements.

Final thoughts

When discussing the potential of NM for the field of palliative care it is important to note that death does not lie outside medicine's story (17). Sometimes it is not even the end of a doctor-patient-relationship: Caring for someone can leave traces of the patient's story in the professional story physicians tell to themselves and others. This is the case with Atul Gawande's recounting of his encounter with Mr. Lazaroff, which is still on his mind after more than a decade and leads him to the conclusion that "*we did little better than Ivan Ilyich's primitive nineteenth-century doctors*" (15).

Being confronted with a life-threatening disease can lead to a lack of words to describe one's own suffering and fear and, on the professional side, to give hope without abandoning the predetermined position. Palliative care is a profession that allows clinicians to engage with their patients in an intimate manner. The complicated emotions that come up when caring for seriously ill people or accompanying them at the end of life may trigger personal memories or even unresolved trauma. For this very reason fictional encounters with death can provide insights, meaning, and they can help to express difficult emotions—in a safe, fictional space that is part of a narrative approach to clinical practice but not directly linked to daily events. Interactions between medicine and literature are primarily based on language and form part of the already complex

research areas of NM and MH. As Siddhartha Mukherjee observes, the reciprocity already begins with the naming of a disease or description of a certain kind of suffering—which is "*a literary act before it becomes a medical one*" (1).

In summary, there are many possible linkages between medicine and literary studies which have yet to be explored. A practice-oriented and interdisciplinary approach to teaching NM-courses in palliative care alongside a permanent integration of NM und MH concepts in the curriculum should be the primary and shared goal of scholars conducting research in the field.

Acknowledgments

Funding: None.

Footnote

Provenance and Peer Review: This article was commissioned by the Guest Editor (Eva Katharina Masel) for the series "Narrative Medicine in Palliative Care" published in *Annals of Palliative Medicine*. The article has undergone external peer review.

Peer Review File: Available at https://apm.amegroups.com/article/view/10.21037/apm-23-252/prf

Conflicts of Interest: The author has completed the ICMJE uniform disclosure form (available at https://apm.amegroups.com/article/view/10.21037/apm-23-252/coif). The series "Narrative Medicine in Palliative Care" was commissioned by the editorial office without any funding or sponsorship. The author has no other conflicts of interest to declare.

Ethical Statement: The author is accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Cite this article as: Edtstadler K. Storytelling & the unspeakable: narratives in/about palliative care. Ann Palliat Med 2024;13(2):452-457. doi: 10.21037/apm-23-252

