HEALING ARTS

Text and Context

Scar Tissue: Dementia's Tangled Web

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J Gen Intern Med 26(4):453-5

DOI: 10.1007/s11606-010-1573-9

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Text and Context consists of excerpts from literature (novels, short stories, poetry, plays or creative non-fiction) followed by an accompanying essay discussing the significance of the work for clinical practice or medical education.

The novel *Scar Tissue* by Michael Ignatieff follows a family through the tensions and upheavals that accompany a diagnosis, decline, and death from dementia. This excerpt from an early chapter describes a family meeting with a neurologist to discuss Mother's test results. The narrator is a philosophy professor. His brother is a neuropathologist, their father a soil chemist, and their mother a painter.

TEXT¹

Three weeks later, we are all sitting in the neurologist's office getting the results, my father, my brother, my mother and I. The doctor is a fashionable middle-aged woman who happens to be a paraplegic in a wheelchair. Beneath her desk I can see her withered legs in a pair of smart black stockings and buckled shoes. With guilty goodwill, I think here at last is someone who will understand.

Looking over the top of her bifocals, she says with a warm smile, 'How are we today?'

Mother says, 'We are fine today.'

'Good, good,' replies the doctor.

'So what's the situation?' my father asks, looking up from his hands.

The doctor smooths open the clinical file. 'Mother,' she says, 'is performing pretty well on some tests, not quite so well on others.'

It doesn't seem right to be talking about her in the third person when she is in the room. I glare at my brother, who rises and escorts Mother out. My brother and the doctor exchange a nod as Mother makes her labored transit to the door.

When the door shuts behind her, the doctor resumes. 'The scans are confirming what you already know,' and here she gestures at the reports. "Discernible shrinkage of the cerebellum, reduction in size and volume of hippocampus, possible evidence of cerebral trauma.'

At the word trauma, my father raises his eyes. 'Must be the car accident.'

'Tell me about that,' she says, taking up a pen. In the shattered silence after impact, I see my father's bloody face lying against the steering wheel and my mother's broken body slumped beside him. Words are resounding in my head, my brother is looking at me, his hands at his temples, blood streaming through his fingers.

The doctor says head trauma, in road accident victims and in boxers, can produce amnesias of Mother's sort. So head trauma is penciled into her list of causative factors, beside heredity, environment, exposure to neurotoxins. She says the more causes that can be enumerated, the more we are likely to understand. Actually, it seems to me, the more causes you can identify, the more mysterious her condition becomes; but I decide not to argue the point. 'Of course,' she goes on, 'the gold standard for all diagnosis in these cases is

'Autopsy,' I butt in.

A thought crosses her mind

'So you know about these things?' she says, brightly. I nod and I don't know whether she is marking me down as one of those tedious neurological autodidacts or as a mature professional she can take into her confidence. Whatever she thinks, she knows I will be doing the talking. My father has withdrawn into a cave of silence.

I ask her the prognosis. She looks at my father's bent head and says, in a softer voice than before, 'Your wife will be dead in three years.'

My father sits with his hands on his knees as if steadying himself.

'I'm sorry,' she says.

She takes my father through the entire *via dolorosa* ahead: which function will break down when, how soon she will cease to recognize us, how soon epilepsy is likely to set in. There is no doubt that she believes such candour is a way of treating us with respect, and I feel grateful for it, but I keep thinking there must be some mistake....

'Take the business about her language,' I say. 'She can't maintain a conversation, but the way she listens, and laughs when you say something that amuses her, nods to let you know she's following what you say.'

The doctor seems interested. 'Her semantic and syntactic memory functions have collapsed, but prosodic variation is still intact.'

'Prosodic variation?'

She means tone of voice, facial expression, gestures. Some patients begin to drawl or stutter in a voice that have never used before. 'They hear themselves speak,' she says, 'and they think who is this?'

¹ Source: Michael Ignatieff, *Scar Tissue*. New York: Farrar, Straus & Giroux, 1994, pp. 55-58. Copyright © 1994 by Michael Ignatieff.

'That's not Mother. She still knows who she is. She may not talk correctly, but she's still able to take part in a conversation. She still has her social skills.'

The doctor is good-naturedly persistent. 'Her prosodic variation is still intact.'

It is the word 'still' that bothers me.

'You keep telling me what has been lost, and I keep telling you something remains.'

'I just see what I see. From the clinical point of view,' the doctor says, looking over the top of her bifocals. There is something admirable about this candour, about this refusal to indulge my hopes. Much against my will, I can't help but like her, though I can tell we see my mother so differently that there is no middle ground between us....

It is pointless to go on and we both know it. The doctor looks at Mother's PET scans and sees a disease of memory function, with a stable name and a clear prognosis. I see an illness of selfhood, without a name or even a clear cause....

CONTEXT

Delivering "bad news" is a much-discussed topic in medicine, probably because it is hard to do well. Unless a physician has known the patient and family intimately over a long time, he or she cannot easily judge the best approach or how the news will be received—stoically, angrily, or emotionally. Too much information can be overwhelming; too little can be frustrating.

Telling the patient and family about a diagnosis of dementia is particularly challenging because it involves the progressive loss of memory, judgment, identity, recognition of familiar faces and objects—all the things that make an individual unique. People come to a family meeting about dementia with different expectations. Many physicians expect to provide their clinical assessment and answer questions about test results and other data. Patients and families expect this information as well, but they are most concerned about how to manage the behaviors that accompany the disease, where to find help, and how to think about the future. Not all this can be accomplished in an initial discussion, of course, but most families expect this conversation to begin. A diagnosis without a plan does not meet their expectations.

Much writing about the "bad news" problem is based on physicians' or families' real experiences, albeit with identifying information changed. The excerpt from *Scar Tissue* by Michael Ignatieff is fiction. Unlike memoirs or case reports, novels and short stories do not purport to be true accounts. Yet, fiction can convey a sense of reality that is as vivid and compelling as a memoir.

In this excerpt, the author's choice of the present tense heightens the reader's sense of immediacy. Dialogue between the protagonists enhances this effect. Unlike a video or a transcript of a family meeting, a fictional account condenses, highlights, and dramatizes the different uses of language, individual reactions, and points of view. Equally important, this technique allows the author to choose what to tell and how to tell it. In *Scar Tissue*, Ignatieff gives the narrator the opportunity to reflect on what is happening while it is happening. We read the narrator's spoken words but are privy to his thoughts as well. Fiction about illness can be judged by its adherence to facts (Could the neurologist really

predict that "Mother would be dead in three years"?) But a more relevant gauge is the novelist's ability to create empathetic links to human beliefs, emotions, and fears.

The passage excerpted here sets out the differing worldviews the protagonists bring to the family meeting. Although the text contains many clinical terms, the true focus is on the lack of real communication between the doctor and narrator. The neurologist represents the doctor as scientific diagnostician. Her role, as she sees it, is to tell the family that Mother has an incurable disease, its ravages visible in brain scans. The narrator tries to understand what is happening to his mother as a person, not just to her brain. Mother herself appears only briefly, quickly taken out of the room by the brother, and Father opts out of the discussion.

This leaves the field free for the author's real purpose—a debate between the neurologist and the philosopher. The narrator tries in vain to explain his perception that Mother still retains some vital aspects of her personality. The neurologist turns his language into clinical terms. "I just see what I see," she says, and what she sees is "discernible shrinkage of the cerebellum." She takes pride in being totally honest (which the narrator grudgingly appreciates). But the narrator wants to go beyond the clinical "truth" and to know what may be unknowable. What is Mother thinking? Who is she now? How can we preserve what remains?

After a long career in England and America, where he was a journalist, broadcaster, historian, international human rights advocate, and university professor, Michael Ignatieff returned in 2005 to his native Canada and entered politics. He is now the Leader of the opposition Liberal Party. The tension between the two worldviews in *Scar Tissue* may reflect Ignatieff's own struggle to understand and accept his late mother's illness and death from dementia.

Ignatieff chose as his title the evocative image of scar tissue in the brain, an image familiar to clinicians. But it must also refer to the scars left by family dissension and accumulated hurts that persist after a long ordeal with dementia that the rest of the novel explores. Ignatieff seems torn between an intellectual interest in the specialists' view that dementia is a "disease of memory function, with a stable name and a clear prognosis" and the more abstract philosophical view that it is "an illness of selfhood, without a name or even a clear cause." This distinction corresponds to Kleinman's well-known discussion of "disease" (a condition of the body) and "illness" (the experience of the person).²

The novelist can separate these worldviews and give his characters words to express them. In real life, physicians have to balance both perspectives in their ongoing communications with patients with dementia and their families.

Questions for discussion:

1. How can a dementia patient's personhood be maintained while the disease takes its clinical course?
2. The neurologist is candid, even blunt, about the sad path—the *via dolorosa*—of Mother's illness. Do you think her

²Arthur Kleinman, *The Illness Narratives: Suffering, Healing, the Human Condition* (New York: Basic Books, 1988).

conversation with the family is a good model for truth-telling?

3. In this fictional family meeting only two people participate. How would you conduct a meeting to hear all points of view, including the patient's?
4. What risks do authors take in fictionalizing aspects of their own experience with illness? Should novels and memoirs be judged on different grounds?

Acknowledgments: Kenneth Covinsky, MD, MPH, University of California, San Francisco, Division of Geriatrics; and Jeffrey Nichols, MD, Cabrini Center for Nursing and Rehabilitation, New York City, provided helpful suggestions on an earlier draft.

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