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Reading and Responding to Stories of Illness & Care

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The stories in *NIB Voices* series are told in many voices, and each raises particular issues. I offer some general questions that might be asked when reading any of these stories.

For those who read the *NIB Voices* stories by themselves, these questions can assist interpretation and maybe introspection that the stories instigate. For those reading in groups, these questions can facilitate discussion. I recommend that groups allow one story to lead to another. Often, the best response to a story is to tell another story.

People tell stories for multiple reasons. Stories told by ill persons and caregivers tend to have some combination of three core goals:

1. How is the story a *call for recognition*? If told by an ill person, recognition may be sought for the dislocation, pain, and specific sufferings of the storyteller. In addition, caregivers--including family, friends, and professionals-- also suffer and often feel their work places fail to recognize this suffering. Thus, a further question: Is telling this story in part a response to the reluctance or inability of certain other people (who?) to offer that recognition? What inhibits that recognition?

2. How does the story offer *guidance* to those who may follow the storyteller and have similar experiences? This guidance is sometimes direct advice, but more often it involves modeling an attitude toward illness and treatment that is the storyteller's hard-won wisdom after a period of searching. The story says, implicitly: *This is who I have learned to be, as best I can be, in the circumstances that I invite readers to share.*

3. How does the story call for *change*, most often in practices of health care? If the story depicts some people acting badly, what are the cultural or institutional bases of that bad behaviour? What needs to change, to avoid suffering that seem unnecessary?

In asking these questions, I recommend keeping two issues in mind.

1. We talk about someone *finding their voice* in a story, or the story as *their own*. That's true in one sense: stories are told not simply to report, but also for the storyteller to *discover* who they can be, as the one who can tell this story ("I tell, therefore I am"). But what people find is not a singular voice:
   - Stories are told in *multiple voices*, and most of those voices are borrowed. Thus ask: in how many voices is the storyteller speaking? (Some of these voices express conventional roles, e.g., patient or parent, spouse or professional.)
   - Other voices express *discourses*. Any illness story begins with medical-scientific language and narrative framings. These are variously rejected, adapted, and added to. Another discourse is what I've called *quest* narratives in which illness and suffering are

occasions for enhanced appreciations. Or, stories can be spoken in a discourse of *political opposition* to practices that cause illness or increase the ill person's troubles.

- How does each of these voices and discourses *serve* the storyteller? Listening requires learning to hear multiple voices, expressing multiple discourses--. how well or badly do they serve? Is part of the story about having learned to silence certain voices that serve badly?

2. Illness stories involve multiple *resistances*. The storyteller must often overcome both internal and external resistances when telling certain truths about illness care, or lack of care. Listeners also bring their own defenses, including everyone's fear that the storyteller's troubles could become their own troubles or the professional's resistance to hearing about inadequacies of care.
    - Paradoxically, it is our resistances to illness stories that also draw us to them: we want to hear the stories while fear hearing them. Listening gets serious when the listener becomes self-conscious about developing a sensitivity to his or her own resistances
    - Ask yourself: what parts of the story am I most likely to marginalize or somehow deny? The parts of the story that we initially ignore or reject are often those that we most need to hear. In group discussions, ask what certain resistances say about who the group is and its presuppositions?

Finally, it's often said that there isn't any right/wrong response to a story. I find that a half-truth. The true part is that stories evoke multiple responses, even mutually contradictory responses. One lesson of some stories is that both sides of a contradiction can be true. But, some responses are wrong in that they fail to account for aspects of the story that are clearly there. Another quasi-paradox: storytellers don't necessarily get everything right, but interpretations & responses need to acknowledge all parts of the story and why telling it that way is necessary for the storyteller.

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