

Commentary: What is at the Center, What the Edges of Care?

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Diseases exert particular constraints on the bodies that bear them. When patients accept that their bodies push them around every bit as much as they do them, they realize they need help: allies, team members, accompaniment. Clinicians can provide accompaniment, a form of compassionate witnessing (Weingarten, 2003), not just diagnosis and treatment. With accompaniment, patients with chronic conditions may more easily come to terms with forming a new relationship to their body even when their understanding of why it is necessary is inadequate; may more readily make changes that can slow the progression of the condition; and may be more able to face the vagaries and uncertainties of health. Accompaniment nurtures hope, which is something people “do” better with others.

What is accompaniment? How do we know when we have it and when we don't?

How can we be sure that we don't want or need it, if it is present; that we would fare

better if we had it when we don't? Can we create it if it is absent; bargain for it if it is

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not? Why or why not? Who is the judge of what counts as accompaniment for whom?
Why does it matter?

To me, accompaniment -- an awkward word, a marvelous experience -- is at the heart of Dr. Lucy Candib's intriguing essay on her search for a diagnosis and treatment of pain in her thumbs. Her essay is less about the diagnosis and treatment per se than the quest for a comprehensive explanation for the pain that dogs her. Despite contacts with multiple allopathic and complementary practitioners, Dr. Candib finds herself in explanatory free fall, framework-less to manage the relentless sensations in her thumbs. Although she finally clicks with a complementary/ alternative medicine (CAM) practitioner, Beth, who practices "integrated" physical therapy, I believe that the essay highlights what we should all expect from good clinical practice more than the advantages of CAM clinicians generically.

Beth is able to accompany Dr. Candib. Beth's observations, recommendations and follow-through match Dr. Candib's internal, perhaps even unarticulated, explanatory model for appropriate diagnosis and treatment. Once matched, Dr. Candib settles in to do work that will provide symptomatic relief and that will shift her understanding of herself, her body, her patients and her role as a family physician. The pain in her thumbs-- these two opposable appendages that she experiences with some indignation for, as she eloquently states it, "you are not supposed to know you have thumbs" -- catalyzes new learning that becomes the occasion for this instructive essay.

The Search For Explanation

Dr. Candib, a family physician and feminist, who describes herself as comfortable with the language of medicine, goes to some lengths to account for her turning toward complementary/ alternative medicine. She does not link this turn to a failure of her allopathic treaters to accompany her. Rather, she tells us plainly that she felt heard and respected by them. She writes, “I felt that each of these clinicians paid attention to my experience of pain in my hands...the conversations I had with these clinicians reflected joint participation in the voice of medicine –for me a ‘mutual lifeworld’ – not the unsatisfactory communication between clinician and patient that excludes the lifeworld.”

Instead her dilemma and concerns center on incoherence and partiality. She is looking for an explanation for her pain that can account for and make sense of sensations she has in her thumbs, restriction in neck movements and recurrent headaches. She intuitively and also believes that these phenomena must be linked in some way: she seeks a parsimonious explanation that is holistic.

Dr. Candib believes that complementary/ alternative medicine (CAM) will provide a better, that is, more coherent, explanation because it offers “an expansion of diagnostic options” (p.6.) While not rejecting Western medicine, she is nonetheless registering dissatisfaction with it or, at least, with how it is practiced. However, she does not make a strong case for CAM meeting her needs. Rather, it is Beth alone among several CAM practitioners – a massage therapist, acupuncturist, and chiropractor – who satisfies Dr. Candib’s quest for a framework and a set of actions logically tied both to diagnosis and to feedback from the symptomatic relief she experiences after trying Beth’s suggestions. Beth provides good clinical care. What should be routine is exceptional.

Why does she seek a better explanation? Dr. Candib asks this question herself, in keeping with the reflexive style of this essay. She notices her noticing, thinks about her thinking, and studies her treaters' clinical notes. Although her musing on this question may have been considerable, she provides us with a limited account and a reductionistic answer. Why does she want to know why she has symptoms? Because, she tells us, she is Jewish, which fits an observation made by Zborowski 50 years ago that Jewish patients seek to understand what their pain means more than they seek relief from it. "Despite my training and experience, my concerns reflected my ethnicity" (p.6).

This is shorthand. Different cultures – like different families – offer particular ways of coping with illness. Jewish culture may emphasize meaning making; another culture, endurance. Both are useful tools. In any case, ethnicity provides a partial account of why Dr. Candib seeks a contextually sensitive, systemic, holistic explanation.

Unfortunately, by identifying her ethnicity as the only cause of her quest, she bisects her concern from what I would consider its source: her disease. As Arthur Frank (1995) has written so eloquently, "The body sets in motion the need for new stories when its disease disrupts the old stories" (p.2). Seeking an explanation is the beginning of the process of constructing a new story. This process is shaped by who we are, certainly, but who we are is now not who we were. For at the moment we perceive that we are in a body that is producing sensations for which we do not have an adequate account, we are in a new relationship to our bodies, or to parts of our bodies. This relationship is defined as much by the new sensations created by the illness or condition as by any enduring characteristic – such as ethnicity -- that we associate with ourselves.

This new relationship, like all relationships, consists of interplay. When we interact with sensations whose comings and goings or intensities or locations are comprehensible to us, we form one sort of relationship. When none of these is predictable, another relationship forms. The relationship to our body is a profoundly intimate one and we all have preferences about intimacy. Diseases, at different times in their life cycle, permit a range of relational possibilities that conform more or less well to terms we can bear. Confronted by terms we don't like – “Bicycle whenever you want, as hard and as long as you wish? I don't think so.” -- we cannot just accept the disease's presence in our lives. We want to negotiate. A coherent explanation for the symptoms we have assists us in negotiating with the disease. It never ceases to astonish me how adept people are at discovering the junctures, moments, at which *their* disease, now not *the* disease, is amenable to negotiation.

By representing disease as a player, I am taking up a point indelibly made by Arthur Kleinman (1988) and Arthur Frank (1995). Illness or disease sets certain constraints. These constraints show up in various ways, including in the narrative we can tell. Influenced by Frank and Kleinman, I have written about the rules governing the story the illness can tell, that is, the different story that can be told if one's illness, for instance, has a known or unknown etiology, is associated with stigma or not, has expensive or inexpensive treatment, or a cure (Weingarten, 1999b). This politics of illness narratives has real effects on the story, the storyteller and the people who listen to it. A person cannot tell the same narrative about a cold as she can about cancer. Nor can she expect a similar reaction. The cold and cancer set certain parameters.

I believe that Dr. Candib's quest for explanation is evoked as much by the way her arthritis manifests itself – the way it first appeared, how it makes her hands feel, the fact that arthritis makes her “know [she] has thumbs,” the activities that it affects -- as it is by her ethnicity. With some diseases she might be quite content to leave it at a diagnosis, and not pursue a reason why. But disease calls its shots too.

In fact, it directs us in ways we do not necessarily attribute to it. For instance, Dr. Candib is able to write about her experience of arthritis with no mention of family members or colleagues. Her arthritic condition allows her to exercise her authorial prerogative to make this essay about a triad – her, her arthritis, her providers – rather than a quartet. Other conditions might not be credibly illuminated without the social context of family, friends, and colleagues. Dr. Candib's account can be understood without knowing how, for example, the person in bed with her, presumably the man she has lived with for 20 years, feels about her wearing splints on her wrists and thumbs at night.

Likewise, her arthritis allows for minimal dependency on her providers. She can choose to visit and then re-visit or not, her family doctor, physical therapist, rheumatologist, massage therapist, acupuncturist, and chiropractor. Her arthritis is not so painful, baffling, or frustrating that it forces her to behave with her providers in ways she dislikes, finds distasteful or despises. (Nor, on the other hand, does it open her to versions of herself she is surprised by or admires.) Her arthritis, apparently, has left her relational world (relatively) intact because she is (relatively) intact. She can move among allopathic and complementary providers feeling and believing that *she* is in charge. Her arthritis, at the moment, permits this perception, which is an illusory self-body dualism most people prefer to believe.

Shuffling the Mortal Coil

Over time, her confidence in her own control erodes and Dr. Candib must necessarily come to terms with life with an unreliable body that does not serve its mistress at every turn (Weingarten, 1999a). Framed in the discourse of autonomy, “there will be a time when I won’t be able to do everything for myself” (p.10), Dr. Candib comes to reconsider her assumption of control. Arthur Frank’s assertion -- “Illness is about learning to live with lost control”-- makes sense to her.

But there are other ways of thinking about the relationship between illness and control. Illness can also expose the illusion that one ever was in control. The metaphor of control collapses because it can only bear the weight of certain kinds of bodies. Bodies that live in impoverished communities, bodies that move in environments saturated with violence, bodies that are disease-ridden do not permit ideas about lost control: you cannot lose what you never had.

Once we accept that our bodies push us around every bit as much as we do they, we realize we need help: allies, team members, accompaniment. We don’t always find it. Candib does with Beth. Beth’s skills – “Beth’s hands know muscles and joints the way my hands know the lymph nodes of a child’s neck, the feeling of a liver edge or spleen tip.” – produce symptomatic relief that permits a particular kind of relationship to form. With Beth, Dr. Candib is willing to make major changes: wear splints to bed; modify her bike, chair, and posture. These concrete changes represent a relaxation into a relationship that holds her. Beth accompanies Dr. Candib as she accepts the undesirable, altered reality that she lives in a body that does not do and cannot do all that she wants it to do.

Accompaniment is a form of witnessing (Hatley, 2000; Weingarten, 2003). With it, Dr. Candib is able to shift into a meta relationship to her disease, to consider not just its inconveniences but its implications. She begins to shuffle the old mortal coil, to recognize her disease as a sign, a prelude, to what will inevitably follow – “that there will come a time when I won’t be able to do everything for myself (p.10).” She will age; she will die. These thoughts humble one. When we step on the escalator of thinking about our own mortality literally not figuratively, it shakes us. The escalator moves in one direction; we cannot get off. Appreciating this may frighten us, even freak us out.

A key observation and insight of this essay is Dr. Candib’s realization that the diagnosis of any chronic illness can provoke a crisis. Clinicians may have a clear hierarchy in their minds of which chronic illnesses are serious and which not, that is, which are likely to trigger a crisis, but a patient is her own N of 1. At some fundamental level, comparison is irrelevant. We live in one body. Supporting her point, her friend, Howard Stein, Ph.D., shared a poem with her that he had composed after being diagnosed with hypertension. He begins and ends the poem with a pithy observation/conclusion: Naming the condition “changed my life.”

He is suffering. It is an important word for all of us to use. In a previous article, Candib writes about suffering (2002). She distinguishes three kinds of suffering, that which derives from disease-related pain; that from the grief that follows losses of all kinds, including loved ones, place and community; and finally, the focus of this important article, the suffering that results from “the memory, both physical and mental...of pain caused by what human beings do to one another” (Dr. Candib, 2002, p. 43). Dr. Candib is clear that working with the third form of suffering obligates the clinician to a very

particular kind of practice, one that she calls “witnessing explicitly” and that I have called “compassionate witnessing” (Weingarten, 2003).

I believe that this current essay can be connected to the earlier one by drawing attention to the importance of the clinician extending “witnessing explicitly,” “compassionate witnessing,” or accompaniment to people who suffer in any of these three ways... and, yes, certainly, to people who suffer from pain in their thumbs or hypertension. However, when a condition is amenable to a full and coherent explanation, the patient’s need for accompaniment from the clinician may not be as great as when the explanatory framework is weak. When the explanation is clear and coherent, others in the person’s social network may be able to provide adequate accompaniment. But when the situation is confusing, it may be only the clinician who can provide the necessary support to the patient and her baffling body.

Support for what purposes? To come to terms with having to form a new relationship with one’s body; to do so even when one’s understanding of the “why” is rough, inadequate, frustrating and unsatisfying. To make the changes one’s body needs to feel more comfortable. To do what one can to slow the progression of the condition. To step on the escalator and “face the uncertainty of health.” When we unpack the phrase “coming to terms with a chronic illness,” this is some of what it means.

Why might a clinician offer this support? So the patient won’t feel so alone as she re-makes the relationship with her body, this exquisite collection of hard-working parts that is our one and only abode as we go through life. Because a clinician is trained to work with a patient and what ails her until the level of analysis that the clinician is using succeeds at producing a treatment that provides the relief. And, finally, because,

when relief does not occur, clinicians have practice with tolerating incoherence and have, or should have, many skills to cope with it, among which should be accompaniment.

Reflections on the Reflections on the Narrative(s)

In this essay, time matters. In 2004, we are reading about a person who has already shepherded her bothersome body through space – work, family life, friendships, leisure activities – for more than a decade. It is in the more recent past, years after her search for a diagnosis began, that she begins to work with her condition through writing (See Penn, 2001 for a masterful discussion of writing in the context of chronic illness.) Now accompanied by Beth, with changes underway, Dr. Candib turns to writing as a resource. She has used it before (Candib, 2001) to turn “private pain into public good” (Weingarten, 2003).

She writes up her notes on her treatments and asks her providers’ to read them. She also requests her providers’ notes. One provider, Terry, a physical therapist, writes comments on Candib’s notes, which Candib reads alongside Terry’s original notes. Reading the writing provides a cooler medium of communication and Dr. Candib learns something that surprises her. Terry did not feel that she, Lucy, was “truly listening” to her. Figure/ground shifts. Our attention is drawn from whether providers were listening to her to whether she was ready to listen to them. Dr. Candib concludes that maybe Terry was right; she hadn’t been ready.

Writing readies her. Preparing to write this essay, reading about herself as someone’s patient -- her symptoms as someone’s clinical challenge – adds a layer of meaning to the sensations themselves. Now, as she prepares to write about them so that

other clinicians may engage with their written proxies, she is hoping that these same sensations that plague her – that she is now making vivid, wrapping them in her carefully chosen words -- will “affect how other clinicians think about and treat patients” (p.10).

Her condition has a job to do now and her writing is its amanuensis. I have taken this route multiple times myself so, to make a full disclosure, I am partisan to this approach (Weingarten, 1994, 1997, 1999a, 1999b, 1999c, 2000). Above all, she hopes that her essay will encourage clinicians to have more patience with the length of time it may take some people to make the necessary changes to manage their chronic conditions. “Don’t give up on them.” “Stay the course.” Accompany them.

What does it take to convey to a patient that we are there for them? How long does it take to get this across? Do we know how to train clinicians to do this? Do we think it matters? Do the economics of the current medical context – time is money- permit the kinds of interactions that communicate accompaniment to the patient? Has anyone measured the cost of failing at accompaniment? Isn’t it (choose: horrifying, expectable) that a discussion of this dimension of care is considered to be at the “edges” of medicine?

Accompaniment nurtures hope. Hope is essential to health (Groopman, 2004; Jacoby & Keinan, 2003). Hope is something that we do with others (Weingarten, 2000, 2003). We can, we must, afford it.

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