

Illness Doula: Adding a New Role to Healthcare Practice

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Abstract In this article, we explore the possibility of adding a new role to the clinical encounter: an illness doula. Even though research and education in medical humanities and narrative medicine have made improvements in humanizing healthcare, progress is slow and ongoing. There needs to be an intervention in the practice of healthcare now for people currently going through the system. An illness doula, like a birth doula, would facilitate and insure that attention is paid to the personal needs and desires of the patient in the present system. We envision illness doulas having the ability and availability to accompany the patient throughout the healthcare process, to help communicate with clinicians, and to ensure that patient preferences are understood and respected along the way. We discuss how this idea emerged through the clinical encounters of two of our authors, the possibilities and limitations of creating a new role for illness doulas, and the logistics of how to put this new role into play.

Keywords Doula · Illness doula · Lived-experience · Patient-centered care · Narrative medicine · Humanism

For the last four decades there have been dedicated efforts to humanize healthcare, to broaden clinical attention beyond biology, and to include human, social, and spiritual variables. New models of medicine have been tried such as patient-centered medicine, the biopsychosocial model, and most recently narrative medicine (Engel 1977; McWhinney 1986; Charon 2006). Plus a library of work in health humanities, bioethics, and disability studies have articulated in

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fine detail the need for including lived-experience and patient choice in clinical encounters and clinical decision-making (Jones, Wear, and L. Friedman, 2014; Davis 2013; Jonsen, Mark, and Winslade 2010).

The early momentum of this work was so strong that Ian McWhinney, a champion of patient-centered care, could ask with palpable hope in 1986, “Are we on the brink of a major transformation of clinical method?” (873). Unfortunately, although some progress has been made, the goal of humanizing healthcare and including lived-experience and patient choice in clinical encounters has turned out to be exceedingly challenging. This article is a meditation on this conundrum based on a case study of one of the authors’ experience with a cataract diagnosis and the friends who tried to help him.

In navigating this experience, it occurred to us that a novel way to work toward the goal of humanizing healthcare would be to introduce a new role into the clinical encounter—an illness doula. Like a birth doula, an illness doula would facilitate and insure attention to patient needs and desires in the present system by accompanying the patient through the healthcare process, helping the patient communicate with clinicians and ensuring that patient preferences are understood and respected. Such engagement would increase the likelihood that the human aspects of the clinical encounter would be valued. Previous and ongoing efforts to educate clinicians beyond biology have their place and may in the long run create the humane medicine many of us seek. But, in the meantime, there needs to be an intervention for people going through the system now. Additionally, this kind of structural intervention into the present system would have the potential to realign clinical dynamics in a way that research and educational interventions have trouble doing.

To work through the possibility of an illness doula, we discuss how the idea emerged through the lived experience of cataract diagnosis and pre-operative work-up from the perspective of the patient and the friend who became a kind of spontaneous illness doula. We follow with some reflections from a working doula. Finally, we discuss the possibilities and limitations of creating a new role for illness doulas, how the role compares and contrasts with similar roles, and some of the logistics of how to put this new role into play.

Lived experience of “the patient”

Like most case reports, I (Brad) will start by saying I am a fifty-seven year old Caucasian married man, employed as a psychiatrist and a medical humanities professor, and living with my family. My present illness and my need to navigate the healthcare system began with a new eyeglass prescription because my vision seemed slightly blurry. The optometrist informed me that she was not able to correct my vision with glasses and suggested I see an ophthalmologist to rule out cataracts. No one in the office could remember the name of the ophthalmologist, but they did have a “card somewhere.” After much looking and asking other people in the office, they found the card. No one knew anything about the person, except that they were “sure he was nice.” After the visit, I called my primary care physician; she gave me the names of two ophthalmologists in her network. Again, she didn’t know much about them other than that they were in her network and she was “sure they were good.”

I wasn’t satisfied with either of those recommendations, so I spent considerable time on the internet looking for an ophthalmologist who seemed like he or she might have decent bedside manner—most of what I had to go on were those questionable internet rating sites and the few physicians who had pictures. Fortunately, the ophthalmologist I saw was reasonably friendly

and collegial. He was able to confirm the diagnosis, and indeed he seemed to enjoy the process. My case was early—I am relatively young to develop cataracts—which sent him into Sherlock Holmes mode, trying to discover the answer to a mystery. He got to use all the different machines in the office, showed me in great detail pictures of my retina, which were more or less beside the point since they were normal, but at the same time they were pretty, and the detail was impressive.

The disappointing part came after the diagnosis was made. The ophthalmologist seemed to have no interest in what came next and did not want to talk about what the diagnosis meant. He implied that I would need surgery, but that I could drive now so I shouldn't worry about it. He would not speculate with me about how long it might take, or when the appropriate time would be to do surgery. He did give me an elaborate "home test" I could use—I could sit in a chair and look at a fixed point, say some books on the wall, and when it reached the point I couldn't see as well I would know I was getting worse. He didn't give me any suggestions on what to do next other than that. A few months later it was clear I was getting worse, no "home test" needed, just trying to get around in the world was test enough. I called the office and scheduled another appointment. The nurse said that there was no point in seeing the ophthalmologist again and that the next step was to see a cataract surgeon. She recommended some surgeons who were in the practice network, but she would not or could not tell me anything about them to help me make a choice. She did not know anyone outside their network. I asked to speak with the ophthalmologist about that, but she said he would do no more and implied that it was not a good idea.

This is where my friend and colleague, Danielle, comes into the story. I had shared with her my experience thus far, and I asked her if she had any insights into how to find a surgeon. I did not want to pick someone from the internet again since it seemed too important. I was hoping to find someone I could communicate with, who had good surgery skills, and who would not over treat me.

Lived experience of “the friend” — pre-visit

Brad first mentioned his cataracts when we were standing in the hallway outside of his Foucault seminar classroom. He was wondering what the shape of surgery would be in his life, how large it would loom. How much space and time would it take? How it would affect his ability to work? Who would he trust to care for him, and how would he make that decision? In the months that followed, the issue hovered in the air like a cloud in a lens, like a simile in a sentence. When it came up in conversation, he would laugh and say that he was putting off making any decisions. He was slow to recognize me if we met in a public place, but I doubt I would have noticed were I not aware that his vision was deteriorating.

I have had many eye surgeries and procedures over the course of my life; my vision is unusual in several respects, but I have adapted, and it is largely unnoticeable to others. I can pass, just as he'd been doing. I felt a particular connection to Brad's experience, that we shared a sense of private vulnerability.

This past summer he asked if I could help find a surgeon. I asked an ophthalmologist friend of mine who is in a highly regarded academic department, specifying that the surgeon should have good communication skills, and he suggested one of his colleagues. He explained that he could personally vouch for her skills and that he would have wanted his own mother to go to her. I noted her academic credentials—residency and fellowship at top ophthalmic training

programs—and passed the information along to Brad. When I asked him about it later in the fall, he said he'd had a consultation but was feeling frustrated as the conversation was mostly with the fellow (a doctor doing specialty training following residency), and he'd had very little time to speak with the surgeon. He wanted to discuss his correction as well, wondering if he could be left slightly myopic, but feared that he'd be viewed as loony and irrational. (In fact, many individuals with longstanding myopia would prefer not to lose their unaided near vision, preferring glasses for distance.) I offered to accompany him to his next consult, and so we arranged to go together.

I teach and write about bioethics and narrative medicine, and I have joined friends and family members for doctor's visits many times in the past, playing the part of scribe, sounding board, mediator, companion, information source, comedian, commiserator, and silent supporter. When I have accompanied people into a clinical encounter, tracking information and fielding questions has always been on the agenda, but beyond that everyone needed something different. My friend M needed me to transcribe her meetings with oncologists and then to laugh together about how her doctor had such immaculately trimmed bangs; at that point, she particularly needed me *not* to ask about certain things, like survival statistics. I would speak up if I felt there was critical information that would be important to make a decision; otherwise I was not to project any sort of agenda. In my experience, this responsibility is much more straightforward with friends than with family members where the emotional entanglements and over-determination is at times inescapable. With friends, even those I love dearly, my duty is clear: I am to be ego-less, in service to their needs, and responsive to what they might need in any given clinical encounter.

Lived experience of “the patient” — doctor visit

My first appointment with the surgeon, Dr. S, was mixed. I left feeling that her medical competence was high, but that she had little to no recognition of me as a person. She was in and out quickly, and most of the communication occurred with her fellow who was green and was trying to pretend like he was not. This left me feeling alone and also worried because I needed help trying to understand what kind of lens correction I should choose. Dr. S felt, and I agreed, that in my case a single focus was the best choice. But, where should it be focused? The usual answer is for distance, but I made a living with close work (reading and writing), plus I had been nearsighted all my life, so maybe focusing close would be the best choice. Dr. S. could not or would not, I'm not sure which, engage with me in this choice. She seemed to think that distance was what everyone did and couldn't seem to understand why it might be different in my case.

I had one more appointment before surgery, and I was feeling worried about the choice. If I didn't have any more luck with communication this time, I would be left alone with the decision, or I would have to go back to the drawing board looking for a new surgeon. I didn't want to decide without help because I felt I didn't fully understand the issues. I tried to find a support group, so I could get conversation with other people who had lived experience, but there were no support groups I could find and I did not know anyone who had experienced the procedure.

I shared all of this with Danielle, and she made the novel suggestion, or at least I had never thought of it, that she come with me for the next appointment. She did not have lived experience with cataracts, but she did have considerable experience with ophthalmology and eye surgery. The hope, and it made some sense, was that with the two of us we might have

more luck getting a real conversation with Dr. S about the lens choice. I was reluctant to ask a friend and colleague for so much help—Danielle has a busy schedule, and this would mean taking a half day off to hang out at the doctor’s office. But I felt at a loss; I had to live with this decision from then on. It felt momentous. So, after double checking a few times to see if she really meant it, I agreed.

I am so glad I did. The next appointment turned out to be very difficult for me. It began with a new fellow who, once again, did not acknowledge me as a person. After some few preliminaries, he handed me some prescriptions for eye drops and started telling me about how I would need to self-administer them a few days before and several weeks after surgery. He said nothing about what was in the drops. When I asked, he said that one of the drops was a steroid. I wanted to know more. I was curious about side effects, if the protocol was perhaps more conservative than necessary, and if it would be possible to reduce the dose and frequency. To my surprise, the fellow abruptly stood up, said that the conversation was becoming “too confrontational,” and left the room.

Fortunately Danielle was there with me, and we tried to make sense of what happened, tried to understand why he felt I was so confrontational, whether I was out of line to ask for more information and for dialogue about the treatment plan. We were in the middle of this when a technician came in and said that I needed some “tests” before I saw “the doctor.” Again there was no explanation, much less informed consent, but I followed the technician. Danielle came along as support. The first few tests were easy and just involved looking in various machines. The tech seemed satisfied but said she needed to talk to “the doctor” to see if she needed more. She came back saying the doctor wanted one more test to get the best “measurements.”

To this day, I have no idea what we were doing, but not knowing quite else to do, Danielle and I followed her to the next room. This time a new technician came in who spoke very poor English and told me to “lie down on the exam table.” She explained that the test can be “pretty hard” but not to worry “the doctor is just being careful.” I did not know what she was talking about, but I did lie down, and she proceeded to put a cup over my eye, which was connected to a computer and drops water (I think) directly into my eye. The technician held the cup over my eye, while the computer beeped. I’m very squeamish about all of this since I have emotional attachment to my eyes. They feel precious to me and at the same time vulnerable, and I am not used to them being treated simply as material objects. The first eye she “tested” went pretty quickly, however, so I hung on. The tech seemed pleased and said, “See, that’s not so bad.”

She then proceeded to go to the next eye, but this turned out to be very difficult. She put on the cup, dropped the water, the computer started beeping, but it never seemed to beep in the right way. She said that she had to try again, that I needed to be more still, and as she pushing the cup down harder and harder, I began to get more and more worried. My eye began to hurt and to feel like it was being traumatized, while the machine was beeping and beeping but never in the way the technician wanted. She was determined not to stop; it seemed that she did not want to tell “the doctor” that she had failed in administering the test. I started pushing back against her arm, but she just pushed harder. The test failed again, and this time I stood up, looked to Danielle for moral support, and we discussed what to do. I told the tech that I was losing confidence, and she implored me to try one more time. The whole scenario repeated and just when I felt I was going to have to physically force the tech off of me, the computer beeped in a new way, and she pronounced we were through.

A little while later, I, now with a sore eye, and Danielle met with Dr. S. There was no discussion of anything that happened earlier; I tried to apologize if I upset her fellow by asking questions, but she brushed it off. We got into another conversation about where to focus the

new lens. Once again the dialogue seemed not to connect. I tried to get a sense of what different focus options might mean after surgery in the different tasks of my life, but she seemed to keep coming back to what she usually says in such circumstances and seemed to be unable or reluctant to think about the particulars of my situation beyond the typical protocols. After getting nowhere, I looked to Danielle to see if she understood or if she had ideas on how to enable a more a more meaningful dialogue.

Danielle had been sitting quietly but was very in tune with what was happening and was now a great help in reframing the question, trying from a different position to engage in a meaningful conversation about my choice. It seemed to me that Danielle was somehow able to break the spell or trance the doctor was in, and sure enough, we all began to talk about what the different focus options might mean. With Danielle there, what was becoming an impasse, shifted into a dialogue. That was the beginning of Dr. S. and I eventually reaching common ground about the best focal point to choose. A little later, Dr. S. left the room, and we were sent to the “surgical coordinator” to arrange a date for surgery. I never did find out the side effects of the steroids.

Lived experience of “the friend” — doctor visit

Stepping out of everyday life to inhabit the role of a patient is profoundly disempowering. One enters a strange new world where the inhabitants—white, blue and green-garbed—speak a foreign tongue, wield sharp instruments, observe an obscure and complex hierarchy, exercise considerable power and authority over all who enter, and are often quick to anger or retreat when they are subject to observations and commentary or asked to engage in equal dialogue. The forces that strip one of dignity and discourage dissent are manifold, yet one is, by definition, entering out of some need and desire for care.

Arriving at the ophthalmologist’s office, Brad and I felt a sense of giddy companionship, putting on our pith helmets, feeling confident in our abilities to navigate this terrain. Yet as he describes, we were in some ways shocked at how many slippery rocks we encountered, how narrow the path proved to be. When that happened, such as when the fellow literally backed out of the exam room because Brad was posing questions about the steroid drops, we were able to turn to one another incredulously and say, “What just happened?”—“Was I really being so threatening?”—“No, your tone was friendly and it was a reasonable question—he was *just* like the Jason character in *Wit!*” Through laughter and commiseration, we girded ourselves and tried to set a positive tone. Yet it seemed like an increasingly dire path to navigate. When Brad was undergoing the last “measurement” procedure, lying prone on the table, asking the technician to stop, he reached out to block her hand just at the moment I was poised to rise from my stool and make her stop. Had Brad seemed unable to speak up for himself or physically incapacitated, or had the technician continued to ignore him, I would have physically intervened, just as I would have trusted him to do for me if our roles were reversed.

In the conversation with the doctor, I felt that my role was akin to that of a mediator, tracking the perspective and apparent motivations of both parties though, to be sure, maintaining primary allegiance to Brad. When the discussion reached an impasse, I sought to acknowledge both Brad and Dr. S and to reframe slightly the question, taking care to project a friendly, conciliatory and hopeful stance. Had I been in Brad’s position I likely would have felt considerable anger and frustration, yet my reactions were tempered because I was not in the primary seat of physical and emotional vulnerability but in service of facilitating Brad’s

experience. I could sense, palpably, that both Brad and the ophthalmologist wished to be understood by one another.

I have a keen memory of our exchange about the refraction question—whether to correct for near, middle or distance vision and the functional effects of each option. Brad was trying to break it down and understand the various advantages and disadvantages, and we seemed to be making progress when Dr. S. interrupted. Brad explicitly asked her, “Please let’s just stick with this, otherwise we’ll lose the thread!”—but she was not to be deterred, offering a mini-lecture about how we were to approach this process which effectively derailed our understanding of the refraction details. We experienced it as an assertion of rhetorical authority, while she clearly felt that she was providing valuable context and information. She also seemed to genuinely care, to be invested in the encounter, and when we were able to break through this impasse, she seemed pleased and relieved, just as we were.

A doula’s response

Just over a week after Brad’s second surgery, in a warm West Village café nearly empty due to the raging mid-February blizzard, I (Annie) met Brad’s newly transformed eyes. Sea glass crystal blue, they glistened and welled with tears as he spoke, as I have always known them to do when he speaks on subjects that stir his emotional tides. Brad wanted to talk with me about his experiences to gain my perspective as a working doula. He told me about his visits to Dr S’ office and about the cataract surgery.

“How was it?” I queried, gently. Brad bobbed his head several times, then squinted, and peered out the window to his left as he told me about the second surgery. “Fine. It was...fine. Well, it was less so than the first time. There was a lot of...clamor. It felt chaotic around me. And I felt like even less of a person to them than I did the first time.” He described the isolation of waiting in the hallway, of not having his family beside him until the recovery period after the procedure. I asked who was there with him in the operating room. He shrugged. He didn’t know who performed the surgery, or who else was even in the room. Strapped onto the wheeling table, IV hooked up and eyes numbed, he said he felt treated like “a slab of meat.” Nobody made themselves known to him, nor was he asked to introduce himself to them.

Listening to Brad’s account of the surgery, I was struck by the simultaneity of anonymity and invisibility with intimacy and trauma. An ache clutched my stomach, an urge to have been there as his doula. What could I have offered in my role as a doula? My mind wove together memories of the abortion, miscarriage, and birth clients for whom I have served as doula with the experience Brad now depicted and stretched forward to envision other patients undergoing a medley of procedures.

“Okay, let’s imagine,” I proposed. “What if a doula had been there for the entire process? Danielle seems to have acted as a kind of spontaneous doula in her work with you at Dr. S’ office. What would a doula contribute to these kinds of illness experiences as a whole?”

I first learned about doulas as an undergraduate enrolled in one of Brad’s classes, “The Philosophy of Medicine.” We watched the film, *The Business of Being Born*, and Brad invited a former student of his to speak to the class about her work as a birth doula. I felt immediately called to all the various components that she described: providing compassionate, continuous care for women through late pregnancy; labor, birth, and the postpartum period; offering informational, physical, and emotional support; and an underpinning drive to reform the healthcare system, empower patients, and promote consciousness and connection during

embodied experiences (Scott 1999, Hodnet et al. 2012, Marshall, Kennell, and Klaus 2012). I began the training and certification process that spring and attending births in the New York area in March 2009. Currently, I serve as a leader of The Doula Project, an organization based in NYC that has spearheaded the emerging “full-spectrum” doula field (Chor et al 2012). We provide compassionate, non-judgmental support to people regardless of the outcome of their pregnancy, whether they face birth, miscarriage, stillbirth, fetal anomaly, or abortion.

My work as a full-spectrum doula is in many ways similar to the work Danielle was doing with Brad. If an illness doula had been formally involved in Brad’s experience, s/he could have been there from the beginning. That beginning might have been during the diagnostic process, after the diagnosis, during the search for additional providers, or nearer to the procedure itself. As when Brad sought Danielle’s recommendation for a surgeon, a doula possessing some expertise in the area could quickly connect the patient with providers who matched his style. If s/he didn’t happen to know providers in that area, s/he could do research and accompany him through the search process to help find the desired connection. However, just as the personalized recommendation for Brad was perhaps not a perfect match, it must be acknowledged that anyone navigating the healthcare system will still contend with its challenges and vagaries.

Once a provider has been chosen, a doula can serve as a mirror, someone from whom a patient can receive validation that what she is experiencing is scary and painful and that she has the strength and courage to do it. A doula can serve as a sounding board, someone to whom a patient can whisper a question or discuss last minute decisions. A doula can serve as an anchor, someone to whom a patient can turn in distress, panic, confusion, or loneliness. A doula can serve as a protector, someone whom a patient can rely upon to recognize, in the worst case-scenario, when his voice is not being heard and his wishes ignored, and facilitate the amplification of his voice.

Navigating an illness or health condition is a stressful and murky experience through which one could greatly benefit from a constant companion. When a patient must make choices—like which provider to work with—collaboration, advice, and reassurance in the decision-making process are particularly advantageous. An illness doula’s steadfast assistance could help a patient circumvent getting the run-around by various doctors, none of whom may have felt like the right match, all of whom may have spoken about things the patient could not quite grasp amidst the swirl of emotions that health concerns trigger.

The overarching goal of an illness doula would be to assist his/her client to create the most desired healthcare experience. S/he would fulfill clear responsibilities, claim a formal title, offer reliable service, possess experience and awareness of resources, receive financial reimbursement for his/her services and time, and stay in the relationship for as long or as brief a period of time as the client desired. The role that Danielle adopted might be formalized into an official illness doula position, freeing both the patient and his/her companions of the complications and burdens entailed when a friend or family member offers support to a loved one in need.

Discussion

Possibilities and limitations of creating a new role for illness doulas

In order to expand the doula role beyond its traditional realm of reproductive experience into a more generalized “illness” terrain, doula training would need to be reimagined. To step into

this larger role, doulas would need exposure to a variety of skills and expertise, or perhaps a doula would choose an area in which s/he were already interested and involved. Regardless, doulas would need to augment their exposure to that field with doula philosophy and practice foundational training, based on the many rich trainings conducted regularly in both the birth and full-spectrum worlds that survey topics including how to provide emotional, informational, and physical support; how to practice non-judgmental compassion; and how to interact with the healthcare system and its many players. Another training of particular benefit for such work could be in narrative medicine which—among other goals—trains providers to listen deeply to their patients—not just with an ear for biological symptoms but with a heart for biographical stories and a keen sense of narrative understanding. Narrative medicine not only equips providers with the tools to receive these stories but also encourages them to engage in self-reflection and healing of inevitable vicarious trauma that providers experience from their work through the writing and telling of their own stories (Charon 2006, Charon et al 2017). Surely, other valuable dimensions, skill sets and perspectives would be of benefit and relevance to illness doula training as well. These are merely starting points for a curriculum as yet to be developed.

Significant benefits would be reaped, by patients and clinicians alike, if we incorporate illness doulas into the experience of healthcare. An illness doula would attend to the systemic issues in healthcare in a way the other current players do not and cannot. S/he would focus on the primary mission of making “patient centered care” a reality. S/he would receive rigorous training to attend to the patient’s humanity, which our current medical education system does not adequately provide the clinicians. Serving in a non-medical role, a doula is freed from the responsibility of biological care that clinicians are best equipped to manage. In this sense, a clinician who is strapped for time and insufficiently trained to provide humanistic care would be alleviated from some of the pressure s/he may feel to serve more roles than one person can. Expanding the team of caregivers by adding a doula would allow all players to excel at their specific tasks – but it would be essential for them to collaborate as a team to provide integrated care. Furthermore, it must be noted that the doula’s compassionate, attentive care for the patient would not replace the need for more humanistic treatment from the clinicians but would rather model it. Clinicians would observe the profound impact of using a soft tone, sustained eye contact, generous listening, and gentle touch.

As a neutral and knowledgeable guide, a doula would endow the patient with thorough and wide-ranging information. S/he would offer the patient a wide range of resources for treatment options that would empower the patient to make a well-informed decision instead of a hasty and reactive choice influenced by biased and pressuring sources. A doula would help the patient claim the position of an autonomous agent. While peaceful dynamics during healthcare delivery are always the ideal, they are not always the reality. If challenging interactions and deleterious actions transpire, a doula could serve not only as witness to the scene and emotional support to the patient but also as an intermediary, mediator, and advocate. A doula would have cultivated a trusting relationship with the patient and possess a deep understanding of his/her temperament, values, and wishes that in a moment of vulnerability, trauma, or chaos the patient may not be able to communicate effectively.

However, there are notable limitations to incorporating the role of an illness doula into healthcare. Ethical and legal complications would need to be worked through concerning the uncertified status of a doula who would be offering information about medical treatment. Hospital protocol may also present hurdles to the inclusion of the doula in protected spaces of the hospital such as like operating rooms, and the efficacy and satisfaction of doulas’ support could not be guaranteed; although research shows that doulas who support women during

labor and birth have a positive effect on emotional and medical outcome, it is impossible to ensure this. Finally the financial piece is also one to consider: if the doula operates in a private-pay model, access to such a support role would be limited to only those who can afford to pay out-of-pocket.

The doula's relationship with the other members of the caregiving team is a crucial dimension to consider. A primary mission for the doula would be to earn trust from the patient, but that does not necessarily translate to trust from the clinical team. S/he may be perceived as an invasive or inferior hindrance by clinicians who already struggle to collaborate with the extensive cast of caregivers involved in medical care. Additionally, while the goal would be for the doula to develop an amicable dynamic with the clinical team, if s/he needs to assume an adversarial role, s/he risks exacerbating the instigating conflict. Finally, while the particular role of illness doula as we have conceived it is new, there are similar roles being explored right now in medicine. How would the illness doula fit in with the other roles already existing?

How the role compares and contrasts with other similar roles

The problem of depersonalization in healthcare and the complexity of navigating the system is widely recognized, and there are an array of innovative responses to these issues. There are already expanded doula options being explored with “end-of-life doulas” and “palliative care doulas” (Corporon 2011, Lentz 2014). In addition, the existing roles of professional “health advisors,” “patient advocates,” and “patient navigators” are designed to fulfill similar roles to the one we are envisioning.

The responsibilities of a “health advisor,” which is a service offered by private services such as PinnacleCare, range from coordinating care to finding physicians, seeking second opinions, researching clinical trials, accompanying clients to visits, and developing “close relationships” with clients. The profile of such a health advisor is typically a registered nurse or a social worker, someone who possesses familiarity with the local healthcare system and demonstrates “a compassionate and caring personality motivated by an opportunity to provide meaningful assistance” (Correspondence: “Health Advisor” Job posting for PinnacleCare Private Health Advisory, circulated July 2015). Increasingly, individuals offer such services as well, like private support in piloting a course through the medical system. Some services specialize in senior care, offering personal accompaniment to medical appointments as well as oversight and advocacy on behalf of the client.

The role of “patient advocate” has been evolving for many years. Established in 1980, a Master's program in Health Advocacy at Sarah Lawrence College (now offering a joint degree in social work with NYU) prepares graduates to work in a variety of settings. Patient advocates are often on staff at hospitals where they can facilitate communication and services for patients. The field has a range of national organizations such as The Alliance of Professional Health Advocates and the National Association of Healthcare Advocacy Consultants. Currently there is neither an accreditation process nor a regulatory body for the field, which continues to evolve. One example of a voluntary code of ethics for health advocacy professionals is The Health Advocate Code, which promotes compassion, knowledge, transparency, and professionalism. Indeed, the Code reflects many of the values we are celebrating in the role of illness doula, particularly that of promoting “client-patients' values and belief systems as the foundation for their decision-making” (<http://healthadvocatecode.org>, retrieved 12/23/2016).

The existence of these professionals who share many of the goals we describe for an illness doula, combined with the evolving state of the field, speaks to the need for developing and refining this important role.

Some logistics of how to put this new role into play

One of the most fascinating features of creating a new role of illness doula is the relative rapidity with which the role could be introduced. It would, of course, take time to introduce the new role into the existing bureaucracy of already standing institutions such as hospitals or medical clinics and insurance coverage. However, if the role were introduced outside these institutions into a free-market service economy, the only limitation would be a market limitation. In other words, is there a market that could be tapped for the services of an illness doula? That answer, we believe, is yes. The frustrations, disappointments, and vulnerability that Brad felt in his experience with the healthcare system are not unusual. Many patients have similar difficulties and challenges.

If these patients knew that there was a person they could hire who would facilitate the process, inform and guide them through the labyrinth of medical sub-cultures, and be an ally for them in times of negotiation and even conflict, it seems likely that many would wish to take advantage of that service. An illness doula would likely increase the cost of their healthcare, but the expense would be worth it for many. And, for some, it would reduce the overall cost because it would help identify excessive spending in the forms of over-testing, over-diagnosing, and over-treatment. An illness doula would be able to take the time to work through the risks and benefits of medical interventions without having any financial stake and better allow patients the opportunity to choose for themselves which forms of interventions are most important for them. This in and of itself is a valuable service.

The other fascinating aspect of introducing the new role of illness doula is the effect it would likely have on the other roles in the healthcare encounter. Since all roles are relational, to change or add one role is to shift the dynamics among all of the roles. There are tremendous barriers to change in an existing large-scale system—each role is protective of its own niche and subject to the regimenting effects of training and habituation—yet an illness doula could act as a key catalyst of change. The most important aspect of how the illness doula would change the other roles is that it would shift the power balance among the different players. At present, despite much effort to counter this, the power balance in the clinical encounter is heavily weighted with the doctor at the top of the hierarchy, the patient at the bottom, and ancillary medical staff in the middle. So many of the sub-cultural rituals reinforce this hierarchy—the patient is often feeling weak and vulnerable because of illness, they are stripped of their clothing, they are often lying down or sitting and looking up at the clinician. The patient is in strange territory, and the clinicians are at home. The list goes on and on. But with an illness doula, this hierarchy would change. The illness doula would be a peer with the clinical team, he or she would be healthy, dressed, and eye-to-eye. He or she might not have the status of the physician, but if he or she feels that the doctor is not a good clinician, does not treat patients with respect and dignity, than he or she can significantly affect that doctor's referrals—this power to shape referrals would be a significant one.

With the power balance more equalized, the chance that the patient will actually be treated as person—as is the goal of all person-centered, humanistic, narrative medicine interventions into healthcare—would increase tremendously. One of the paradoxes of medical care is not so much that doctors do not know how to treat people as people (rather than a collection of body

parts), it is that they compartmentalize this human capacity. Medical personnel can treat their friends and relations as people, but they have more trouble with patients. But, if the patient suddenly had beside them a person empowered in the form of an illness doula, then immediately the situation changes. It is no longer a clinician talking to body parts, it is clinician talking to another clinician. Instantly, the dynamic has changed, and the chance of real human to human communication goes up dramatically.

Conclusion

Despite the preliminary nature of this proposal, we believe that the key issues are sufficiently worked out that the role of illness doula can be taken seriously and the possibilities of implementation can begin. Clearly many more details need development but it is possible now to provide these kinds of services. As illness doulas and patients gain experience working together to narrate and navigate the healthcare system, further studies of this new role can emerge. Throughout the process of developing this role, the key idea is simple. In addition to improving patient-centered care through research and education, the goal of empowering patients can rapidly accelerate by providing patients with well-informed illness doula companions. Moreover, ongoing efforts in areas like healthcare communications, health humanities, and narrative competency will also continue to be important. The big difference in adding an illness doula to the team is s/he will dramatically increase the motivation of clinicians to actually effectively put patient-centered skills into practice today.

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