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The Person in a State of Sickness

The Doctor-Patient Relationship Reconsidered

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Abstract: In this article, we discuss the ideas of Eric J. Cassell about the patient-professional relationship. We argue that his approach combines in an interesting way features from the literature on patient autonomy and paternalistic practices. We suggest that these seemingly paternalistic features of practicing medicine, which are widely either ignored or condemned in bioethical discussion, are of vital significance in medical practice. In the first sections of the article, we describe the main features of Cassell’s understanding of the sick person and his version of personalized medicine. We pay particular attention to his notion of information control and compare his ideas about conversation with patients to Hans-Georg Gadamer’s analysis of patient-professional dialogue. In the latter part of the article, we explore through a couple of examples the implications these ideas have for medical practice.

Keywords: Eric J. Cassell; patient-professional relationship; patient autonomy; paternalism in medicine; Hans-Georg Gadamer

The Sick Person and Impaired Functioning

Eric J. Cassell practiced medicine for almost four decades, and his books draw on his rich experience of attending to patients. In this article, our focus is on his arguments in his newest book, The Nature of Healing. A central notion of the book is that of the person, more precisely the sick person, which is crucial for Cassel’s argument: “Almost nothing about persons . . . is unaffected by sickness. What sickness does is impair function, but the functions that it limits are found in every sphere of a person’s life as it is lived.” Cassell argues that medicine that focuses on functioning is inevitably patient centered. He describes the person as an embodied, relational being who responds to meaning in light of goals or purposes. Impairment of function inevitably affects persons because it affects their ability to pursue their goals.

This characterization of sickness as impairment of function leads to a person-centered approach to medicine that requires attentive listening to the narrative of the person seeking medical help. The patient’s story is likely to reveal the functional impairment that hinders her in the pursuit of her purposes. Cassell’s book demonstrates this with several stories showing what the impairment is doing to a person’s life. The temporal dimension of narrative reveals the processes of functioning that tend to be covered up in the static language of pathophysiology, which reduces the impairment to a function of body parts. “Perhaps the problem to be solved is reductionism itself,” Cassell writes, because it isolates the sickness from the lived experience of the person. He finds it “amusing” that the “personalized medicine” that has recently come into fashion in relation to tailoring of medical treatment to the genetic variation of individuals takes an equally reductionistic attitude toward people in terms of their genetic makeup.
Cassell uses the example of rheumatoid arthritis to show that “there is a natural progression from the events in pathogenesis and pathophysiology to the story of impaired joint function, then impaired limb function, and the impaired person’s function.” The physician has the opportunity to change the story by helping to restore the impaired function, which returns the patient to desired activities and contributes to his or her well-being. This is the sole goal of medicine, and it is radically personal, according to Cassell, because “only the patient can know whether he or she has a sense of well-being.”

The well-being of patients is inextricably related to their intentions and goals, and treatment decisions must take that into account. Therefore, medicine cannot be practiced efficiently without a good knowledge of the person and the meaning the sickness has for him or her. This is well described in the following passage:

Janet Abraham, an experienced oncologist and now a palliative care clinician, has pointed out that in discussion about whether a patient with late stage malignancy wants third or fourth level chemotherapy the wrong question is usually asked. The issue is not whether the tumor might shrink 10% or something similar, but what the patient wants to accomplish that the treatment and a physician focused on function might make possible.

This implies that decisions about treatment cannot be made independently of patients’ goals and purposes. “That means knowing a lot about patients and what things mean to them.”

Cassell relates the move toward “patient-centered medicine,” now universally accepted but not as widely practiced, briefly but positively to the bioethics movement. It was partly due to bioethical discussion that emphasis was turned on the patient as a person—attempting to save the subjectivity and whole of the patient from the clutches of the objectification and reduction that inevitably follows specialization in medicine. With this came a demand for truthfully informing patients, enabling them to make decisions regarding their treatment, leaving traditional paternalism behind. “Respect for persons has helped move the idea of persons and knowledge about them to a more central position in medicine. From this it follows that healers and other clinicians should know as much about persons as they know about their pathophysiology.”

Cassell relates his understanding of respect for persons to the prevailing understanding of it in the bioethical literature. A common and popular interpretation of the demand to respect the person is to translate it into two versions of “respect for autonomy.” In their famous text, *Principles of Biomedical Ethics*, Tom Beauchamp and James Childress usefully distinguish between negative and positive obligations to foster a person’s autonomy. The negative obligation centers on noncoercion, a requirement that calls for “appropriate specifications” and “valid exceptions” in particular contexts. The positive obligation, on the other hand, aims at fostering autonomous decisionmaking, primarily by disclosing adequate information.

Cassell is in agreement with the aims of this way of respecting persons and their autonomy. “I believe it means that where sick persons are concerned, respecting autonomy will require other people to help the sick patient by, at least, providing information, ensuring that it is understood, and making sure that the sick person’s
The Person in a State of Sickness

choices are voluntary.” Even though it is not explicitly criticized, this model of respecting the person is revealed, however, as quite limited in light of Cassell’s characterization of the sick person. The “cognitive” emphasis on providing information to make a considered judgement and making sure it is understood is important in the case of sick persons, but it requires an approach that takes their situation into account.

The finding that the cognition of bedbound sick patients is impaired . . . does not mean that they lack capacity to make judgments that are in their best interests, it means that their healers and other clinicians must be very careful in finding out what the patient believes is in her best interest. It takes time to determine what these patients want because of the constraints on decision making.

Conversation with Patients and Information Control

As can be seen from the preceding discussion, Cassell does not reject the understanding of respect for persons in terms of autonomy. On the contrary, he talks about it as a “vital task” to make sure that “a patient’s expression is autonomous—of opinion, choice and presentation of self.” Cassell’s approach, however, implies a radical criticism of ways of respecting patients’ autonomy that do not take their status as sick persons into account. “Patients in a state of illness are full of uncertainties,” which seriously affects their cognitive capacities. Cassell is very critical of the idea, sometimes presented in the bioethical literature, of presenting patients with choices regarding their treatment and expecting them to make considered judgments. “It is not fair to ask someone to reason well who cannot . . . . Please do not give a cafeteria of choices because you believe patients should exercise their autonomy . . . . To repeat, it is not fair to simply lay out information and then ask the patient to make the decisions.”

It is commonly acknowledged in the literature that because of the impaired status of the sick person, relatives should be present when information is conveyed to patients. This is primarily done to ensure that patients will receive and understand the information about their condition. When Cassell writes that doctors should not have patients “make such choices by themselves,” he has something much stronger in mind about the patient-professional relationship. He focuses on the role of the doctor and his work with the patient. “The healer becomes the source of connection and knowledge and the healer becomes the patient’s agent of control.” The healer’s helping role is quite different from ordinary, everyday help, Cassell argues. It requires the formation of a close, we-are-in-it-together relationship. “It is with the professional self that the healer is forming a ‘we’ with the patient.”

This is striking because the use of “we” is often taken to demonstrate a paternalistic attitude toward patients, that they are treated as children who cannot be trusted to do things on their own. Cassell emphasizes that patients are not children, but he argues that the cognitive impairment in most patients means that they are not in control. That’s why the joint effort of healer and patient is needed to restore the patient to autonomy. The goal of the “we” is to show the patient that he or she is not alone in the task of regaining functioning; in contrast, a distant and neutral approach can have the effect of abandonment. From this perspective,
respect for persons requires not only truthfulness in conveying information but also “the patient’s trust in the truthfulness of the healer—trust, always, that the healer has this patient’s best interests as a paramount guiding force.”

One way to demonstrate the characteristics of this relationship is to see how Cassell describes communication between doctor and patient. “Communication with sick patients is not ordinary conversation,” Cassell writes, emphasizing that the doctor is working, “working at making a sick person better.” He characterizes this work as “information control” and argues that three main objectives should guide the way in which information is conveyed: “First it should reduce uncertainty. Second, it should improve the patient’s ability to act. Finally, it should improve the relationship between physician and patient.” If the physician does not have the practical wisdom to be guided by these objectives, the information given may well undermine the relationship and leave the patient in a state of uncertainty and paralysis.

At first sight, at least, this may seem to be different from other accounts of respectful conversations between doctor and patient. It is instructive, for example, to compare and contrast Cassell with Hans-Georg Gadamer on this point. Gadamer distinguishes between three modes of the “I-thou relationship.” The first is characterized by an objectification of the other, the second by a premature understanding of the other, and the third by an openness to the other. Gadamer’s objectifying approach is roughly similar to what Cassell labels the “reductionistic” attitude toward the person. Cassell also warns against features in the doctor-patient relationship that are characterized by premature understanding of the other, emphasizing that the doctor needs to attentively listen to the narrative of the person seeking medical help. This is necessary for the physician to understand the patient’s situation and to gain insight into how the functional impairments are experienced by the patient. This requires attitudes that are similar to Gadamer’s “openness to the other.”

However, there are features in Cassell’s discussion of doctor-patient communication that are different from Gadamer’s account of the I-thou relationship. Gadamer describes this as the importance of the meeting of the dialogical partners in the subject matter. This is the task of conversations: “To conduct a conversation means to allow oneself to be conducted by the object to which the partners in the conversation are directed.” Among the preconditions for conversation is that neither the patient nor the physician should be preoccupied with his or her own objectives; rather, they should forget themselves in the movement of the dialogue itself. This is because, for Gadamer, the main objective of conversation is understanding, and in that process both partners must be guided by openness to the other and to the subject matter. These factors are certainly important for Cassell as well, but from his perspective they would only form part of the story. In addition, physicians must take a more methodological approach, as it were, that makes the conversation an inseparable part of their clinical work.

It could be said that Cassell’s approach combines clinical techné, in which the physician is “working at making a sick person better,” and communicative praxis, listening attentively to patients and respecting their point of view. This is why “communication with sick patients is not ordinary conversation,” and here we encounter again features that are often associated with paternalistic attitudes. Cassell explicitly says that “information is itself a therapeutic tool and is meant to benefit persons.” One precondition for communication of this type is the patient’s
trust in the truthfulness of the doctor: the patient should trust that the physician has “this patient’s interest as a paramount guiding force.” This information management requires that doctors do not forget themselves; on the contrary, they must be very vigilant in making sure that the information given “is tuned to the ability (at that time) of the patient to process the information.” It is in line with this that Cassell says that, as a rule, he does not tell patients things but responds to their questions. “That way I knew they were ready. The trick was to get them to ask the questions.”

The picture that emerges from this description is rather different from prevailing descriptions of the patient-physician relationship in the bioethical literature. The main difference is that whereas the bioethical discussion focuses on the decisionmaking part of the relationship, Cassell is concerned with the therapeutic aspect of it. After all, “we seek the aid of physicians to treat our disease.” This does not mean that Cassell ignores the decisionmaking aspect; in fact, he seems to regard shared decisionmaking as the appropriate model of the patient-professional relationship. He is, however, very critical of “the contemporary manner” of leaving patients alone to choose among complex alternatives so as not to impede their autonomy. In this way, patients are “exposed to unnecessary uncertainties” that undermine their autonomy instead of strengthening it. His descriptions show that together the doctor and the patient “make an appropriate decision-making unit.” However, by placing his analysis radically in the clinical context, the decisionmaking is so intricately linked with other aspects of the healing process that it cannot, and should not, be isolated from them.

Cassell does not frame his ideas in terms of moral theories, but it seems to us that important aspects of them can be captured in the Kantian language of respect for persons. Kant distinguishes between a negative and positive formulation of this fundamental moral requirement. The negative requirement is better known: the perfect duty to treat humanity in one’s own person or in that of another never merely as means but always at the same time as an end. In the context of the doctor-patient relationship, this translates into obligations not to manipulate by some kind of deception or coercion.

It is not as clear, however, what the positive obligation to help persons to achieve their ends implies in this context. It has been convincingly argued that positive respect for persons need not merely imply facilitating personal informed choice, as emphasized by Beauchamp and Childress. What is of major relevance is that the end of healing that is implied in the doctor-patient relationship should guide our understanding of the positive obligations. Framed in that light, the primary obligation is not to facilitate the patient’s deliberation of information in order to secure a considered choice but rather to contribute to restoring the patient’s functioning. This is the overarching end of the doctor’s information control.

Implications of Patient-Centered Medicine for Practice

Even more importantly, Cassell’s approach—in addition to being theoretically relevant—has radical practical implications for medical practice. How can personalized medicine in the true sense of the term really be practiced? It requires multiple virtues and skills on the part of the clinician, who is asked to forge an unusual closeness with patients in order to empower them. The clinician must first of all elicit the relevant information from patients about how their functioning is
impaired, how their sickness is preventing them from pursuing their goals and purposes. It is most instructive to demonstrate this with an actual case example.

Siri has suffered from arthritis for many years. The doctor, who is having his first consultation with Siri, cannot rest content with establishing the diagnosis and learning which of Siri’s joints the disease has attacked. Basing his response on the fact that the disease has affected Siri’s shoulders, knees, hips, and ankles for more than fifteen years, the doctor might prematurely conclude that Siri is badly off and insist on her taking one of the potent drugs that have become available in recent years for the treatment of arthritis. The person-centered doctor, on the other hand, will make sure to ask Siri how the arthritis is interfering with her functioning. Siri’s answer is that as long as she allows between one and two hours in the morning for her pain and stiffness to subside, she is perfectly able to attend her work as a teacher, which means a lot to her. She even walks home from work twice every week. This takes more than one hour and is a great source of well-being. “I’m used to the pain, it doesn’t really affect me. And I’m able to enjoy nature a lot, although I can’t do rough hiking like I used to,” she says.

A doctor primarily focused on diseases or drug treatment who witnessed this account could still have insisted that Siri is in need of medical treatment. The person-centered doctor, however, is aware that Siri’s own evaluation of how the arthritis is interfering with her goals and purposes is crucial. When a doctor with that perspective pursues his inquiries, it turns out that Siri is quite knowledgeable about how rheumatoid arthritis can mutilate peoples’ joints, as well as the significant amount of monitoring required when people take potent drugs against arthritis, as these drugs can have serious side effects. Siri herself judges that she is not heavily afflicted, as she is able to walk—albeit slowly—home from work twice a week, in addition to making easy excursions into nature, and to do her work, where she enjoys success and fulfillment. Furthermore, Siri’s narrative includes defining herself as a healthy person rather than as a patient, and thus she does not want to use strong medications on a regular basis. Therefore, although Siri experiences pain and stiffness every day, most of the time her ability to pursue her goals and purposes is not strongly affected by her arthritis. However, every once in a while one of her joints will swell and become exceedingly tender. On these occasions Siri’s functioning is strongly impaired, and she is grateful that her doctor can then inject an anti-inflammatory drug into the affected joint, as this usually enables her to start pursuing the activities that are important to her within a day or two.

In accordance with Cassell’s plea—“that healers and other clinicians should know as much about persons as they know about their pathophysiology”—the clinician in the preceding example needs to engage with Siri about her functioning and well-being. The communication skills needed for that task are the backbone of the so-called patient-centered clinical method that actually has been incorporated—to some extent—into the curriculum of medical students and graduates in many countries. Since the 1980s, ideas about “patient-centered medicine” and similar concepts have matured into a full-fledged clinical method that has gradually been implemented in teaching at different centers. Core components include communication skills for eliciting from patients their own beliefs about their ailments, how they anticipate that professionals can help them, what they fear about their health and their life situation, and their values and goals. For this purpose, the patient-centered doctor employs a set of open-ended questions...
that have been shown to be suited to helping patients share the relevant information about themselves as sick persons.

Second, this clinical method includes combining the preceding information about the patient as a person with conventional biomedical information to engage in a dialogue with patients about how they can best be helped. The communicative methods appropriate for such shared decisionmaking involve explicitly acknowledging the patient’s perspective and engaging the patient to do as much as possible of the reasoning and negotiations needed. It is well established that this patient-centered clinical method improves patient and doctor satisfaction, and to some extent it has even been shown to improve patient health outcomes. Its gradual implementation in teaching and healthcare is a noteworthy challenge to conventional technology-driven and disease-focused approaches.

The Doctor-Patient Relationship Revisited

There is an interesting tension—almost paradoxical from a bioethical viewpoint—in Cassell’s descriptions of the patient-professional relationship; this tension combines features from patient autonomy and paternalistic approaches. The patient’s goals and purposes are to be the guiding light of this relationship, but the doctor is nevertheless supposed to actively manage the information provided to the patient. Cassell’s descriptions of this information control clearly imply that the relationship between the doctor and patient is an asymmetrical one. But how is the doctor to judge what the patient should know, and what is the moral source of the doctor’s authority to withhold or “edit” information?

This issue can perhaps best be explored through another example. Olga is an elderly woman suffering from multiple diseases who frequently goes to see her general practitioner. At the beginning of today’s consultation, Olga complains that the doctor has not yet referred her to a specialist for one of her diseases, worries that she has not taken any blood tests recently, and wants another drug for the pain and cramps in her legs. The doctor hesitates and then makes a response that surprises Olga. With gentle concern, he suggests: “Perhaps it is time we take a break from all those specialists. Your blood tests have not revealed anything significant for the last five years. Maybe, together, we need to consider a different approach. Do you think it possible that your social isolation and unhappiness might be having an impact on your pain and poor health?”

Olga is outraged. For the rest of this consultation and during the following weeks she seriously considers finding another doctor who is more sensitive to her complaints. She feels rejected and finds it humiliating to discuss her social isolation and the way her family has treated her. Nevertheless, she sees her doctor three more times, and gradually the “we” composed of Olga and her general practitioner explore Olga’s life situation, her mental health, and how these are interlaced with her requests for multiple medical investigations and treatments.

In this patient-doctor relationship, Olga was requesting, and expecting, a certain type of response from her doctor, such as, “All right, I’ll refer you to the gynecologist and order new blood tests today, but I will really have to take a close look at your medication list to make sure the new painkiller I want you to try is compatible with all the other drugs.” Instead, the doctor chooses to challenge Olga with the new and unanticipated impression that recent responses to her ailments have not been helpful and presents her with the hypothesis that Olga’s experience
of poor health may be exacerbated by her social situation, and that she might even be depressed.

In this situation, as well as in many others, the professional duty of the doctor “working at making a sick person better” is to look for approaches that might help the sick person, even to the point of challenging and provoking if this be needed. He or she must ensure, however, that his or her suggestions are “tuned to the ability (at that time) of the patient to process the information.” Among other things, the doctor must not challenge patients beyond the limits of their trust in the doctor. The doctor must know enough about the patient to make an educated guess that from the patient’s perspective the challenge does not appear irrelevant or unsurmountable. In the case of Olga, the physician presumed correctly that the patient had sufficient trust to realize that her doctor had “this patient’s interest as a paramount guiding force.”

One aspect of the asymmetry between the doctor and patient that comes to the fore in the preceding example is that the doctor’s position allows an insight into the patient’s health, personality, and social situation, enabling the doctor to draw some tentative conclusions that initially are not visible to the patient. Using their professional expertise in their patients’ interests, doctors have an obligation to help patients achieve their goals; and patients need to accept that doctors may offer unanticipated information and perspectives.

In Olga’s case, she had been unaware of how she was contributing to her social isolation and of the degree to which it contributed to her health complaints. Although Olga was not bedridden, or as cognitively impaired as some of the patients with life-threatening illness that Cassell describes, nevertheless, her problems were of such a nature that her own resources were not sufficient to grasp their complexity, resolve them, or identify the course of action that might help her.

Being a patient means that person’s health is afflicted; thus the course of action that will improve the person’s well-being is—to some extent at least—beyond the power of the individual person, and therefore the intervention of a professional is called for. This intervention should increase the person’s autonomy—sometimes by physical intervention into the patient or his environment, sometimes by helping the patient become clearer about the appropriateness of his own ends and actions, or sometimes by a combination of these. As Edvin Schei has highlighted, the vulnerable role of the patient implies that the doctor must take a certain leadership, which is “displayed as discerning, empowering improvisations in critical situations, based on empathy and willingness to learn from patients.”

What, on the other hand, are the constraints of the power that is granted the doctor to intervene on behalf of the patient? What moral limits are there to the doctor’s power to dictate information and actions to the patient, and what are the practical manifestations of these limits? Cassell’s simple answer would be that in “working at making a sick person better,” the doctor must keep in mind that the goal is not to be in the right or only to achieve mutual understanding as described by Gadamer. The sole goal of the doctor should be to restore the impaired function that returns the patient to desired activities and thus contributes to the well-being of the patient. And a crucial thing about this goal is, according to Cassell, that “only the patient can know whether he or she has a sense of well-being.”

On the one hand, the privileged position of doctors allows them to hypothesize about what will be useful for the patient, including how to control the information given to the patient when it would be helpful for him or her to see things differently.
The Person in a State of Sickness

On the other hand, because only patients experience their own well-being, it is the patient and not the doctor who is the final judge of whether or not the paternalistic elements in the doctor’s work lead to success.

Conclusion

Relying on Cassell’s analysis of the impaired functioning of the sick person, we have argued and demonstrated through examples how medical practice often requires that the doctor take decisive control of the situation. Paradoxically, this implies that the doctor employ apparently paternalistic measures in order to empower the patient, enabling him to reach his goals and purposes. The reason for this resides in a radical asymmetry in the doctor-patient relationship, such that the condition of the latter is often characterized by profound uncertainty. We have argued that the role of the doctor is to contribute to restoring the patient’s functioning, thus enabling her to reach her end. We have also argued that a precondition for such medical practice to be respectful of the patient is that it be truly personalized in the sense that the aim of the treatment is guided by knowledge of the patient’s own goals and values and is centered on her concerns.

Notes

2. See note 1, Cassell 2012, at 50.
3. See note 1, Cassell 2012, at 64.
4. See note 1, Cassell 2012, at 62.
5. See note 1, Cassell 2012, at 4n.
7. See note 1, Cassell 2012, at 59.
8. See note 1, Cassell 2012, at xiv.
9. See note 1, Cassell 2012, at 63.
10. See note 1, Cassell 2012, at 143.
11. See note 1, Cassell 2012, at 255.
12. See note 1, Cassell 2012, at 236.
13. See note 1, Cassell 2012, at 240.
14. See note 1, Cassell 2012, at 236.
15. See note 1, Cassell 2012, at 189.
17. See note 1, Cassell 2012, at 189.
18. This can be seen in various guidelines for communicating bad news to patients.
19. See note 1, Cassell 2012, at 92.
20. See note 1, Cassell 2012, at 92.
21. See note 1, Cassell 2012, at 91.
22. See note 1, Cassell 2012, at 239.
23. See note 1, Cassell 2012, at 181.
24. See note 1, Cassell 2012, at 181.
25. See note 1, Cassell 2012, at 182.
29. See note 1, Cassell 2012, at 181.
30. See note 1, Cassell 2012, at 181.
31. See note 1, Cassell 2012, at 238.
32. See note 1, Cassell 2012, at 239.
33. See note 1, Cassell 2012, at 239.
34. See note 1, Cassell 2012, at 239.
36. See note 1, Cassell 2012, at 102.
37. See note 1, Cassell 2012, at 102.
38. See note 1, Cassell 2012, at 102.
39. See note 1, Cassell 2012, at 102.
41. See note 1, Cassell 2012, at 255.
43. See note 1, Cassell 2012, at 239.
44. See note 1, Cassell 2012, at 239.
46. See note 1, Cassell 2012, at 181.
47. See note 1, Cassell 2012, at xiv.