

Continuity of Care From a Patient's Point of View: Context, Process, Relation

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Background: *It is easy to forget about the real human experience when faced with the pressure of output measurement, organizational change, and large-scale statistical studies. This article takes a different perspective and provides a glimpse into one man's life to show the many relationships that can be involved when someone is ill.* **Methods:** *The information in this paper is based on interviews with multiple individuals involved in the care of one patient. The theoretical framework is narrative—it takes discourse as its material base—and introduces the concept of the “signifier” to organize the data.* **Results:** *The interview results demonstrate the theoretical strength of the signifier concept and reveal the process and context of the work of three particular physicians and the nature of the relations they were able to establish with this one patient and his son.* **Conclusions:** *This way of conceptualizing the process of care from the patient's point of view enables us to reflect on the changing nature of continuity of care as a core value for family physicians.*

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I would like to introduce you to a useful concept^{1,2} and show how I have applied it to the question of continuity of care. The case study presented in this paper was produced during an ongoing inquiry into continuity of care from the patient's point of view. The method that generated the case derives from a program of research known as “science in action,”^{3,4} which takes a network approach to the field of study. In this case, a series of interviews have provided the information that underpins the story. By bringing in the concept of the “signifier,” we can begin to count the gaps that exist between what is said, what is meant, and what is heard, which allows us better to account for the human dimension in health care work.

Methods

The Case Study

The interview was one of a series I conducted with patients and caregivers in the offices of physicians in London. The interviewees were selected by the office staff, under the guidance of the physician. The story was told by “A,” a young man (in his early 30s) who was caught up with trying to care for his father's rap-

idly degenerating health following a stroke. Eight years ago, A's father had a heart attack while on a visit to the United States. After his return to the United Kingdom, care was successfully transferred to a cardiologist who was able to maintain the ongoing care of this patient both in his private practice and through the arrangements made possible by the National Health Service (NHS). The relationship between the patient and the cardiologist was maintained over 8 years in different conditions and different locations, but the ongoing relation between the physician and his patient continued.

Two years ago, the son noticed that his father's behavior had become a little strange. This prompted a consultation with a family physician, the result of which was a referral to a geriatric psychiatrist. The psychiatrist works in a different hospital from the cardiologist. Relations among the three physicians (the family physician, the cardiologist, and the psychiatrist) were conducted according to the principles established in medicine over the years. That is, the link is maintained through the shared discipline and training of medicine, marked by the practice of letter writing, and there is no other immediate institutional or social link between any of them.

After a year of relatively low-key care, the father underwent a series of tests that indicated the presence of dementia. At this point, questions about social services became more pressing, and it was here that the

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son made one of his most serious complaints about discontinuous care.

Before going into the details, it is important to describe a bit more of the arrangements under which the patient received care. The son wanted his father to be allowed to continue living in his own apartment (a separate apartment to that of the son but in the same block), thus creating the possibility that the son could participate in the process of care. This arrangement also brings the geriatric psychiatrist and his team into a relational arrangement with social services. These two parts of the team (social services and the psychiatrist) are rooted in different institutional structures, as well as in different theoretical disciplines, such that much of the effort to create the "team" depended on personal good will of those involved.

When the son spoke to the interviewer, he said that his father had been badly let down by social services. The meals on wheels, the home help service, and the social worker were all held responsible by the son for a failure in care on the day when his father suffered a stroke, which resulted in his spending several hours lying on the floor of his home without any help at all. This catastrophe left quite a deficit in the relationship between the son and the social worker throughout the following year, which effectively blocked any good will or creative energy that might otherwise have helped to resolve problems as they arose.

Then a second crisis occurred. The father's ankles swelled up to such an extent that A asked his family physician to make a visit. The family physician, however, was not in a position to leave her office and asked her associate to go in her place. This second physician duly arrived and made his assessment but concluded that there was nothing to worry about and left. A couple of days later, the son's concern again reached a peak. He returned to the family physician, who again declined his request to visit, this time citing her colleague's opinion that nothing was wrong. However, a few hours later, she changed her mind and telephoned A to say that she was on her way to visit A's father in his home.

This home visit led to A's father being admitted immediately to the local hospital where a special ward had been set up to care for primary care patients. The ward is run by nurses and operates in an "overlap" between the hospital and the community. It happens to be in the same hospital where the psychiatrist works, and to the average layperson, it would seem that the overlap ward and the community hospital were part of the same administrative system. But they aren't, and the son was most perplexed when he discovered himself shuttling back and forth between the hospital, the overlap ward, and the physician's office to make sure paperwork and orders were transferred properly.

A took his father out of the overlap ward, and he is now an inpatient in the psychiatric ward. They travel

across town to consult with the cardiologist in his private practice. A was able to press the cardiologist to write a letter to physicians in the psychiatric ward to resolve a problem with A's father's ankles. Through this intervention, A felt relieved that he had been able finally to ease some of his father's suffering.

The Concepts and Demonstrating the Approach

I would like to introduce the concept of the "signifier" and indicate how I have made use of this concept in analyzing this case. The concept of the signifier was introduced by Saussure² in his innovative work developing the then-new science of linguistics. The way I have taken it up here follows the work of Lacan,⁵ who formulated the following definition: "A signifier represents a subject for another signifier."⁶ We can represent the encounter like this:
$$\frac{S^0 \rightarrow S^1}{s}$$

The large S stands for signifier and the small s for signified. For the purpose of our inquiry, I am going to designate one S as S-zero (S^0) and the other as S-one (S^1). This will help us to hold the structure and keep the son's story at the center of our attention. If the son is S^0 , then the S^1 can change with each different interlocutor. For example, in the interview, the son is represented as S^0 and the interviewer as S^1 . The small s appears under the line to indicate the lack of access we have to the father and to indicate that he is in a passive relationship to our story. We can use the same formulation to represent the way that the son (again S^0) also participates in the process of care on behalf of his father (again, s) in his dealings with, for example, the cardiologist (S^1), the psychiatrist (S^1), the family physician (S^1), and so forth.

Each pair of signifiers can be investigated in three more ways. The first is the context. For example, the son speaking to the cardiologist is a different context from the son speaking to the psychiatrist. The second is the process. Different things will happen according to whether it is the cardiologist, the psychiatrist, or the family physician who is being spoken to, and different things have to be done to maintain the process. The third is the relation, which itself can be divided into two parts. First, each of the three medical specialists shares a relation with the son that is based on their access to greater knowledge of medicine and to the resources available in the systems of health care. The son comes to them because he needs something they have, such as their knowledge and their organizational resources. A second kind of relationship exists between the son and each of the three specialists, and these are based on something particular to the people involved and the context of each one of them, details of which are personal and must be treated with discretion.

One further important assumption of this approach that must be explained is that the signified is not com-

pletely captured and not absolutely defined by the signifier. We know, for example, that the son is speaking to a researcher about the process of his father's care, but we also know that he cannot say everything about that process: there is the gap between the signifier and the signified: S/s . There is also a gap between what the son says to the researcher and what the researcher understands, represented by the arrow ($S^0 \rightarrow S^1$).

Over the course of about 2 years, the man (our subject's father) had gradually succumbed to the effects of dementia and had become less and less able to speak for himself. If we use the concepts here, we could say that the father became less able to be his own signifier—his ability to represent himself is affected by his illness. His body and his speech increasingly manifested the signs of his illness. These signs became increasingly more the business of the specialists involved, as the son became increasingly less able to interpret the signs on his own. The specialists, with the aid of their training, experience, and institutional resources, came increasingly onto the scene, introducing elements and procedures into their patient's life to ease his suffering and sustain his survival. The work of these experts, understood through our theory, took signs from the patient's body and turned them into signifiers that linked the illness to their particular regimes of cure. We can see, now, how the small s in the equation is subtly but importantly different depending on which signifier (above the line) is representing what to whom. The father, the patient, the dementia, the problematic vascular system, and the swollen ankles are each slightly different "subjects" produced between two signifiers, and circulating in discrete discourses, but all of which grip onto something real at the site of this particular human body.¹

If we follow the swollen ankles here,⁴ we could say that the son is reading a sign from the body of his father but that he fails to translate it into a signifier that can address the S^1 , which is taken up by his family physician. The physician who visited and examined the ankles did not judge them a valid sign for translation into his specialized discourse. The staff in the primary care ward did not read the sign in this way either. What might we say of the son's reading? Perhaps we could say that he was picking up a sign that his father needed more help than he was getting, but he failed to translate that into a signifier that could easily transmit its meaning to the correct other signifier. He had something to say but did not clearly know what it was nor to whom he should address it.^{7,8}

It is, nonetheless, interesting to follow what he did do. He took his father out of the hospital and traveled across town to the private office of the cardiologist, where he kept an old appointment that had been made for quite another reason. Here he asked the cardiologist to write a letter to the hospital to authorize the in-

creased dose of diuretics that would reduce the swelling in the ankles. The cardiologist hesitated, was a little reluctant, remarking that surely there were experts at the hospital that could do this? We can use the same interpretation that was made with the visiting physician—the signifier used by the son was not finding its target in the signifier held by the cardiologist; he was not the right S^1 . But then something else happened. The cardiologist acquiesced; he agreed to write the letter. The son described this (during the interview) as a huge relief. The pressure that was building up in the son was given a way out, via this letter. The act of the cardiologist transformed the son's disquiet back into trust, which then followed the letter back toward the psychiatrist and his team.

What had happened? None of the physicians involved in this scenario seemed to be unduly worried by the swollen ankles. The son was overwhelmed with the significance of them, however, and he remained emphatic that someone deal with them. The hesitation and ensuing action of the family physician and the cardiologist are indicating something barred to us, below the line of signification (in the place of the lower case " s "). They both hesitated when called to act in terms of their pure discipline. They each, then, go on to respond within the trappings of their discipline.

Conclusions

The concept of continuity of care is usually invoked to express something important and essential about the relationship between physicians and patients. The hypothesis would be that, through the existence of a history, a process, and a context, a relationship had been established between physicians and patients that enabled the physicians to continue to act well even when it is not at all clear what is wrong, to be aware of something that is only present between the lines. We saw here how two of the physicians (the cardiologist and the family physician) reacted to something beyond the formalized limits of their discipline, but each, nevertheless, acted within the formal procedures of their discipline. It is only possible to make sense of this if we acknowledge that the symbolic order of discourse cannot capture everything, that there are lacks. It is in these spaces that a physician (or a son) is obliged to continue to be able to think, act, and improvise, even when there is little possibility to fully grasp what is going on.

Each relationship among the son and his father and the different physicians had been established under different conditions and through a different process over particular periods of time. Each context and process was governed by the principles each different physician has of working, which in turn was affected by the differences in the nature of each kind of specialization. There were also differences in organizational framework that each had to work within. All of these differ-

ences—the disciplined work of each physician and the formalized legal, economic, bureaucratic, and technocratic orders of the organizations—are essential elements of the symbolic order in which health care is carried out. What is done with the spaces, how much room there is, and the nature of relationships that ties them together, are all still discussions that need to be had. The important thing, as I hope this case has demonstrated, is to establish them as vital and essential parts of the scene and to provide a first concept with which to approach them.

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Palliative care incorporates the whole spectrum of care – medical, nursing, psychological, social, cultural and spiritual. A holistic approach, incorporating these wider aspects of care, is good medical practice and in palliative care it is essential. Reassure about continuity of care. Discussing admission to palliative care units / services. discuss palliative care in the context of how it can help them achieve their goals. e.g. You have told me you would like to... Palliative care may be able to help you achieve what you want. emphasize the positive aspects of palliative care. Discuss a DNR order in the context of the patient's view of their future. e.g. You have told me you would like so CPR would not seem appropriate if you died. If necessary, discuss