Making communication research matter: What do patients notice, what do patients want, and what do patients need?

Ronald M. Epstein *

Departments of Family Medicine and Psychiatry, University of Rochester School of Medicine and Dentistry, 1381 South Avenue, Rochester, NY 14610, USA

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Abstract

Objective: To explore limitations of current communication theory by considering different perspectives of researchers, clinicians, patients and teachers of communication.

Method: Theory development based on limitations of the current communication research literature due to inconsistencies between patient reports and observed communication behavior.

Results: While researchers focus on the mechanics and techniques of communication, patients seek relationships in which they experience trust, the right amount of autonomy, caring, and expertise. Patients’, physicians’, and communication experts’ perspectives do not always define the same problems and often point to different solutions.

Conclusions: In addition to studying clinician behaviors and patient perceptions of care, communication research should focus on five additional factors: what patients notice, want and need, and how their perspectives differ from those of physicians and researchers; the context, including illness severity and type and family influences; how complex health systems facilitate and impede communication; patients’ influences on physician communication behavior; and habits of mind that promote attentive care.

Keywords: Communication; Physician–patient relations; Research; Qualitative; Quantitative; Mindfulness

1. Introduction

Those who teach and research communication in health care have the opportunity to understand health care encounters from several perspectives. As researchers, we can observe the process of care through a variety of theoretical lenses. As patients, we can experience the same types of suffering and emotions that afflict anyone seeking care. Researchers who are also health professionals can appreciate health care from the perspective of a clinician with a body of knowledge, opinions, and clinical experience. Seeing the same encounter from those different perspectives can uncover assumptions, inconsistencies, and limitations to the theories and research methods that we commonly employ. For example, in thinking about my own health care experiences and those of my family, the time spent with the physician in an examining room constitutes only a portion of the experience. The rest of the experience is framed by discussions with family members before and after seeing the physician, aspects of the practice such as whether the receptionist seemed warm or friendly, and how difficult it was to schedule the appointment. Those factors are often ignored in communication research. The physician is also often oblivious to those factors—but patients are not. As a patient, I tend not to be very concerned with the mechanics of communication, only that I feel understood.

In this article, I will examine how clinical, health systems, and patient factors affect physicians’ communication behaviors, and how considering these factors may help reconcile communication theory and research with the
experience of patients seeking health care. I will propose some recommendations and directions for communication research. In addition, I will suggest how understanding the role of individual and institutional mindfulness—habits of attentiveness, curiosity, flexibility, and presence—can enrich communication research.

2. Perceptions of patients

I injured my hand on July 31 while repairing a bicycle. I had just arrived with my family at a cottage in a very rural area, 50 km from the nearest hospital. The lever that adjusts the height of the bicycle seat broke off while I was trying to tighten it. The metal impaled my hand, just below the thumb creating a 2 cm jagged laceration with profuse bleeding. We drove to the emergency room of a small rural hospital, the quality of which I did not know.

I arrived in the emergency room, and went to the desk of the receptionist. He did not greet me. Rather, his first words to me were “date of birth”. From his perspective, I imagine that was a very sensible question, as the date of birth might be the easiest way to access information in their computer system. However, from my perspective, I began to worry. Was that the kind of caring I was to expect? He was not particularly interested in me, just in getting a task done.

I was momentarily reassured when the physician then came in, introduced himself and listened very attentively to the story of the injury. But, then he told me that because it was a puncture wound, he would likely not sew it up. He explained this carefully, using simple language to make sure that I understood. However, he had not seen the wound yet, which I believed would certainly change his mind. I knew that he was wrong and that the laceration would need stitches. But, I felt too timid to speak up, at least at that moment. I suppose that I hoped that he would realize his mistake once having seen the wound.

A recording of the interaction would have received high marks using any of a number of communication coding systems—empathy, validation, open-ended questions, and clear advice. But, a critical ingredient was missing—he had not looked, and thus, his conclusions were wrong and he lost a patient’s trust. His communication might have appeared impeccable, but his care was inattentive.

Returning to Rochester, I saw a hand surgeon, as I still had some residual numbness on the radial side of my thumb. He was friendly and conscientious. He was accompanied by a resident and a medical student. He started to explain that numbness on the radial side of the thumb is of minor significance compared to numbness on the ulnar side. He did not use technical language, and his explanations were very clear. From his perspective, it made sense—he explained to the resident and student that the ulnar side is involved in fine manipulations such as screwing in a nut or holding a brush. However, he did not ask me what I do with my hands. For pianists and harpsichordists, the radial side assumes more importance, because it is the side that makes contact with the keys. Again, his communication appeared good, but did not meet the needs of the patient. This time I spoke up, perhaps because of my need to make sure that the trainees did not make the same mistake as their supervisor. I said, “I guess, for me, though, things are different, because I am a serious amateur keyboard player”. The doctor agreed, but not after having lost the confidence of a patient—albeit a very critical one.

Patients notice different things than physicians [1,2]. They notice when their physicians seem caring, interested, attentive, and present. They notice respect, accommodation, flexibility, and understanding. They notice when the physician’s tone of voice seems confident [3], but, interestingly, assign different values to self-confidence depending on whether the physician is a surgeon (in which case self-confidence is a good thing), or a primary care doctor (in which case, partnership seems more important than confidence). They notice when the physician has addressed their fundamental concerns, not taking the first one mentioned as the most important. Patients notice their physicians’ overall style.

It is not clear how and when patients notice the expression of power in clinical encounters. One argument for studying interruptions, for example, is that are thought to represent the physician’s efforts to maintain control of the discussion, allowing physicians, not patients, the power to assign importance to some data that the patient presents, and not others. One of the most widely quoted studies on medical communication [4] was an observational study of residents interacting with their primary care patients. It was designed to demonstrate the effect of “interruptions”, defined as any utterance that elaborated on the patient’s story, repeated the last words the patient said, or provided a statement or an answer that was inadequate discussion of a concern. In a secondary analysis of the data, Makoul et al. found that some utterances that we coded as interruptions had neutral or positive effect depending on whether the physician is a surgeon (in which case self-confidence is a good thing), or a primary care doctor (in which case, partnership seems more important than confidence). They notice when the physician has addressed their fundamental concerns, not taking the first one mentioned as the most important. Patients notice their physicians’ overall style.

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to be facilitative—in particular, asking open-ended questions—were the worst offenders. It seemed that any kind of question created the obligation of an answer, perhaps because reciprocity is a cultural norm. The implications of these findings alters what we might teach clinicians—to utilize completers and avoid open-ended questions that invite reciprocity early in the interview.

Patients may notice only global attributes rather than individual behaviors. A popular small airline company in the USA, which has received high customer satisfaction ratings on every aspect of their service, also received very positive ratings on their meal service. However, that airline does not serve meals. Patients, like air travelers, may assign positive or negative attributes to their physician on the basis of extrapolation from a global gestalt rather than direct observation; the patient thereby avoids the cognitive dissonance of ascribing poor communication skills to a physician whom they otherwise like. Thus, it is of interest which qualities and characteristics of physicians induce those global judgments. Although what is said may explain part of the variance in patient ratings, some of their ratings may be influenced by factors that have little to do with communication, such as race, gender or socio-economic status [6].

3. Wishes of patients

The second case is of a relative of mine, “Nancy” who was recently diagnosed with breast cancer.1 After a routine mammogram showed a suspicious lesion in December 2003, she underwent needle biopsy of an area suspicious for cancer. The pathology report described non-invasive intraductal breast cancer. This was reasonably good news to the physician, as the prognosis would be excellent. The patient was devastated. She was scheduled for lumpectomy and sentinel node biopsy followed by radiation and tamoxifen. Chemotherapy was not planned because the tumor was small and assumed to be low risk for spread.

Lumpectomy (late December) was complicated by significant postoperative pain. “Nancy” felt that her discomfort was not taken seriously, and her calls to her surgeon were not answered promptly. She noted swelling then dehiscence of the wound with drainage of copious purulent fluid. She was left with an unanticipated scar. She was told that this was an unpreventable complication of surgery.

Pathology of the surgical specimen differed from the needle biopsy; the tumor now appeared more aggressive, but was still thought to be a small tumor (3 mm), without spread to adjacent lymph nodes. She completed 6 weeks of radiation therapy. It was medically “uneventful”, but she described the staff at the radiation oncology clinic as unfriendly and uncaring; she felt like she was treated like “a piece of meat”.

She asked me, as a physician-relative, whether she should have a second opinion. I arranged consultation with an oncologist and a breast cancer pathologist in another city.

There was a 2 week delay in sending the pathology specimens to the second pathologist. The new report differed from the previous one, suggesting that the tumor was larger and more aggressive (6 mm, high-grade). This finding was transmitted by telephone between the two oncologists. Either there was no written report sent to the pathologist, or the report was ignored.

Despite several worried phone calls, her primary oncologist did not discuss this discrepancy with the patient until radiation therapy was completed—nearly 6 weeks later. She met with the patient and insisted that chemotherapy be begun immediately, without offering a choice to the patient. Of note is that, in such situations, the American Society of Clinical Oncologists consensus document suggests six options for treatment for patients with localized breast cancer with aggressive pathology and lesions larger than 5 mm, without any basis for making the choice beyond so-called “patient preference”. The patient, startled by the change in recommendations, did not agree to chemotherapy, and indicated that she had not started tamoxifen either—due to fear of menopausal symptoms. Further discussion was planned for mid-March.

Before this could occur, “Nancy” developed sudden shortness of breath and right-sided chest pain. She was admitted to hospital on a Friday afternoon. A CT scan of the chest was obtained, which showed no disease in the chest, but an initial “unofficial” reading reported five lesions in the upper liver “characteristic of metastatic disease”. “Nancy” was told that these were most likely metastases, and that she would need mastectomy, oophorectomy, and chemotherapy. In hospital, her symptoms improved quickly without treatment. She was scheduled for a CT-guided needle biopsy of the liver to confirm the diagnosis. Upon reviewing the CT on Monday, a senior radiologist called the diagnosis into question. The liver biopsy was cancelled and an abdominal magnetic resonance scan was ordered; however, the patient was not informed why. The scan suggested that the tumors were likely congenital and harmless, and that there was no evidence of metastasis.

A bone scan was ordered, “just to make sure”. It showed an area of uptake in one rib on the side opposite to the primary tumor and the pain—it otherwise was normal. A positron emission tomographic scan was ordered, and, 2 weeks later, it was read as negative. It was now 5 months post diagnosis and the patient had not yet started tamoxifen and had not decided about adjuvant chemotherapy.

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1 Reported with permission from the patient. Her name has been changed to protect confidentiality, and some events are reported with more detail than others in which her care was exemplary.
Unhappily, “Nancy” was not the protagonist in this drama. Rather, she was reduced to an object of care; she became a problem that needed solving rather than a human with a history, an opinion, and a future. The fragmentation of the health care system made failures of communication almost inevitable, and led to unnecessary and harmful testing, and treatment. In the face of uncertainty, the oncologist was unwilling or unable to reframe the situation from to see it from a new perspective. The oncologist lacked the quality of a beginner’s mind, in which possibilities are not limited by prior formulations. She was not present, physically or emotionally.

Like most patients, “Nancy” valued information, perhaps even more than empathy. A recent study [7] suggests that, even more than good communication skills, women with breast cancer want respect, trustworthiness, and expertise. The qualitative analyses of interviews with these women suggested that they seemed want an “attachment figure”, and that our focus on the mechanics of communication and informed choice may be misguided. They wanted a sense that someone is control, but did not necessarily want to exercise that control themselves.

But, her situation was more complex. “Nancy” wanted information, but the situation was clouded in uncertainty. Rather than providing choices, the oncologist tried to reassure her by providing the illusion of certainty. The oncologist rigidly promoted one option, rather than inviting give-and-take from the patient to arrive at a consensually formulated plan. When her efforts backfired, the patient lost trust.

Even behaviors, which are defined as good patient-centered communication habits may be inappropriate in some settings. Sharing of information is presumed to be “patient-centered” because experts presume that patients want it, patients generally say that they want it, and it can enable patients to participate more actively in medical decisions. Offering patients choices is also thought to be a way to engage patients in their care. Patients may lose trust when physicians verbally express uncertainty [9,10]. If trust is compromised, is the communication still to be considered “good”? This puts physicians in a double-bind—if we try to maintain trust by withholding information, are we being unacceptably paternalistic? These findings are not only true of older patients who are typically more deferential to physicians than younger patients, but also to patients, who, if questioned, would value autonomy and involvement in their own health care.

Despite calls for partnership and 20 years of the evidence-based medicine movement, in a recent literature review, we found virtually nothing in the medical literature that might guide physicians in how to discuss clinical evidence with patients on an individualized basis [11]. In that paper, we proposed some guidelines for communicating about clinical evidence, that include ways of presenting evidence verbally and graphically, using numbers or qualitative terms, assessing the patient’s information needs, and building partnership. These suggestions remain to be empirically validated, though. It is clear that when information is shared, consideration should be given to helping patients and physicians tolerate uncertainty. It is not clear how to accomplish this. Decision aids seem not to have lived up to their promised ideals of creating partnerships that would lead to wiser decisions [12]. This may be because there is little guidance for physicians on how to communicate with patients to frame the use of a decision aid and interpret the results.

4. Needs of patients

My second attack of kidney stones was in 1988. In the emergency room, a well-meaning resident asked me what the matter was. I said I thought I was having another kidney stone. I was very uncomfortable. As people typically do when they have kidney stones, I was writhing on the stretcher trying to find a comfortable position. The emergency room physician took my self-diagnosis unquestioningly, then asked me what dose of narcotics he should give me. Recognizing me as a colleague, I think that he was trying to give me some control over the situation with the offer of participation in medical decisions. But, at that moment, despite the years of medical training, and expertise in pain management, I could only reply, “Just give me something”! The autonomy being offered seemed like an impossible burden. My cognitive abilities had been so affected by pain that I could not think clearly.

Cognitive capacity of seriously ill hospitalized patients may be severely compromised; the average level of cognitive function in one study was about the level of a 10-year old [13]. That is, they functioned barely at a “concrete operations” stage, in which conservation of mass was not understood, and the subjunctive uninterpretable. This finding has implications for communicating with patients in intensive care about whether to attempt aggressive care, or to let nature take its course. Some patients simply need to be taken care of. They need be relieved of the anguish not only of a kidney stone, but also of the realization that they cannot make even a simple decision.

But patient passivity in other circumstances is undesirable. In chronic disease, patient outcomes are related to the degree to which patients are involved in their care. Patients with HIV have forced dramatic improvements in their medical care by demanding greater involvement, often to the chagrin of their physicians. Interventions in which patients
are coached to interact more assertively with their physicians [14], and interventions to increase patients’ self-efficacy suggest that activated, self-efficacious patients do better [15]. Even older patients, who typically take a more passive role in communication, can benefit from patient activation interventions [16]. Presumably the same would be true of the poor, immigrants, non-English speakers, and other marginalized groups. Even though they might not want to be activated, it seems that they need to be in order to optimize outcomes that are of value to them.

5. Conclusion

Several principles of communication can be derived from the preceding examples. First, health systems have a powerful influence on communication and patients perceptions of it. Regardless of communication behaviors, patients value their relationship with their physician on the basis of availability and being on time [17]. Even small things—a receptionist who was more involved with the computer than with the patient—make a difference.

Second, patients influence communication. When I spoke up during my visit with the hand surgeon, he acted differently thereafter. When I asked my physician to make a decision on my behalf while I was in pain, he did.

Third, context matters. No one theory of communication or set of communication guidelines can account for the diverse situations in which communication occurs in health care. Even within a given patient–physician relationship, communication behaviors and the principles underlying them change depending on the nature of the patient’s illness. The sociologist, Flyvbjerg, suggests that sociological and psychological theories become meaningless without considering context [18]. By inference, multiple theories are necessary to describe and prescribe communication behavior.

Fourth, perceptions of communication behavior depend on whether one takes the perspective of a patient, a physician or a researcher. Patients’ impressions, for example, may be affected by factors extrinsic to communication, and extrinsic to the patient–physician relationship; expert perspectives may be biased by theories that are applied to contexts for which they were not developed [18]. Patient, physicians, and researchers may notice different aspects of communication, resulting in competing theoretical implications.

Fifth, there are some clinical habits of physicians that promote good communication. These include attentiveness, curiosity, flexibility, and presence [19,20]. Informed flexibility and the ability to see a situation with new eyes can enhance communication and diagnostic accuracy [21].

First, communication research should reflect a realization that we don’t practice medicine in a vacuum. Most patients, like “Nancy”, communicate with family members and friends before, between, and after medical consultations. Most patients have a friend or relative who is a health professional; sometimes they bring that person along with them [22]. One study that addresses this issue is a recently-completed randomized trial comparing accompanied with unaccompanied visits. The study results suggest that fears that family members might dominate conversations to the detriment of the patient’s agenda appear unfounded [23]. This is the beginning of a line of inquiry that should investigate other contextual aspects of communication.

Second, we need to understand better the health systems factors that facilitate or inhibit effective communication. Some health systems seem designed to impede effective communication. The receptionist in the emergency room was not trying to be rude; he just did not understand himself to be part of a healing environment. The pressure to shorten office visits may inhibit communication and participation in care [24] while increasing discretionary diagnostic testing [25]. Ordering a test is one way of truncating discussions that may be seen as an attempt to reassure the patient rather than explore his or her concerns in depth. Reassurance without explanation often has the paradoxical effect of making patients feel dismissed and more anxious [26]. Ethnographic methods have been helpful in studying the influence of the structure of clinical settings on health services delivery, including communication [27]. New methods are needed to study these complex interactions.

Third, communication is a two-way street. We are just beginning to understand the influence of patients on their physicians. Patients who use more assertive responses and ask more questions induce patient-centered communication behaviors in their physicians—their doctors tend to use more partnering statements [28]. We need to know how and when to share complex clinical evidence with patients—both when they ask for it, and when we think that they might derive some benefit from knowing. This bi-directional—or multidirectional—model of communication requires contextualization of the theories upon which principles of good communication are based. Communication requires input from clinicians, patients, health systems, and the prevailing culture.

Fourth, we need to explore the qualities of mind of individuals and systems that predispose to good communication. Mindfulness consists of at least four qualities—attentiveness, curiosity, flexibility, and presence. The receptionist in the emergency room was not attentive. The physician was not curious—he thought he knew the answer before he looked at my hand. The oncologist facing uncertainty was not able to be flexible in the face of conflicting and shifting data. Being flexible enough to invite the patient to state her preferences in the decision making process, and being curious enough to elicit the patient’s values may have avoided miscommunications and angst.

6. Research implications

These observations have some implications for communication research.
Presence is physical and virtual, it can be a sense of connection that transcends place and time. E-mail access to one’s doctor seems to ameliorate the isolation that impersonal health systems can impose, and create a sense of virtual physician—the doctor who is with you all the time, albeit asynchronously [29–33].

Weick and Sutcliffe have introduced the idea of “mindful systems” [34]. They define these as “heedful” inter-relationships that produce a sense of collective mind in organizations so that individuals can collaborate on complex tasks. They describe some of the characteristics of systems that seem to function well in settings where even small errors can lead to disaster, such as on aircraft carriers or operating rooms. Those characteristics include a list that could apply to whole systems as well as to the individuals within them. He advises acting as if systems tend to fail, especially those that involve communication. Not assuming that problems that arise will be unanticipated and that they will depend on unique conditions and context leads to the importance of resilience and responsiveness in the face of the unexpected. Taking the view that problems are likely to be unexpected, tolerance of complexity and ambiguity, informed flexibility and avoidance of excessive standardization become paramount. Open communication including non-punitive reporting of errors can help avoid blame and allow individuals to learn from mistakes, rather than hiding them. Critical curiosity is a quality of mind that allows a practitioner or a health care team to try to understand problems rather than dismiss them. Mindfulness research, on both an individual and an organizational level, may help to explain the gap between what physicians think they do and what patients experience.

Finally, communication research should move beyond the deficiency model—that is, proving that physicians don’t do enough of this or that. We know that physicians don’t do enough of most things. For example, the average adult patient has 15 risk factors and 25 preventive recommendations [35]. The average patient in primary care might spend 60 min or less of total contact time with a physician over the course of each year; healthy patients have less. Physicians choose, consciously or habitually, among competing opportunities to provide elements of good care. Research might better focus on synergy—how accomplishing one goal might facilitate the achievement of another, albeit indirectly. The physician who effectively motivates a patient to change her diet may have made the first step in encouraging exercise, even if there is no evidence that it was discussed.

New themes for research in communication and health should be context, systems, bidirectionality, and mindfulness. These themes overlap. Considering context, taking an organizational perspective, understanding patients’ influences on physicians, and fostering mindful awareness will help communication researchers to appreciate the nuanced realities within which clinicians practice and the uniqueness of each of our patients’ lives.

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References


