

# Chapter 7

## “T” Is for Transparent



### 7.1 Opening a New Channel for Communication

IOM rules for the new healthcare [1]:

4. “Shared knowledge and free flow of information.” Patients should have “unfettered” access to their own medical information and to clinical knowledge relevant to their health.
7. “The need for transparency.” Their health system should make all information available that is relevant to patients making informed decisions including possible alternative treatments. This should also include information about stakeholders, effectiveness, and costs of the health system and its components.

The “chasm” of miscommunication between doctors and other health professionals on one hand and some of their most complex patients is often substantially bigger than the health professionals can imagine. During my many years working as a behavioral health clinician and behavioral science teacher in primary care, I sometimes heard stereotypes about doctors from patients, descriptions that seemed completely at odds with my experience of the family physicians, both faculty and residents, that I worked with. “They are only in it for the money.” “They all talk to each other and they never go against each other.” “They don’t care a bit about us if we aren’t rich.” “We are just guinea pigs for them.” I tried to understand how this difference in perception of their doctors between myself and these patients would arise, especially since the family doctors I knew were, as a group, the most idealistic professionals I ever met. Occasionally the explanation might have been that the patient was angry at not being prescribed the pain medication or benzodiazepine they thought they should have. Often the patients had been through negative experiences in the hospital or at an emergency department and were generalizing to my primary care colleagues (see Chap. 5). It was clear, however, that these patients still experienced their contacts with their doctors as alienating. Nothing about the idealism or benevolent communication skills of my family physician colleagues seemed to impact the negative generalizations that these patients maintained.

When I talked to the family medicine residents I was teaching about the level of disaffection of some patients in primary care, they were polite, but I am sure they thought I was being overly dramatic. They had encountered few if any patients whose behavior would give credibility to my descriptions. The patients who made these bitter statements to me, a professional who was not a physician, showed a much more compliant and less bitter side of themselves when they met with their doctors. They often failed to adhere to elements of their treatment plans, but they did not show overt alienation in their visits with their doctors. These were usually people who had lots of contact with doctors. They had multiple chronic illnesses. Many were disabled. They had behavioral health problems and often had a history of trauma and substance abuse.

The research that was centrally important in Chap. 5 [2] confirmed my experience that often patients with complex medical and behavioral health issues, with low socioeconomic status and poor education, and with histories of traumatic childhood and adult experiences feel alienated and distrustful. They can experience contact with their physician as an uncomfortable interaction between people of very different social class and position power. Because they are hesitant to share their ideas, requests, or reactions with their doctors, their doctors often have little clue about the depth of the communication chasm. These patients are not transparent with their doctors. The doctors, for their part, are more likely to be directive and less likely to use approaches such as shared decision-making with these patients and so are less transparent with this population [3, 4]. Bridging the communication chasm is crucial to caring for these patients. It appears that transparency is needed in both directions. To foster transparency in both directions, the health professionals have to go first.

## 7.2 A Call for Transparency

Transparency is addressed by rules #4 and #7 of the 10 rules for a new healthcare articulated in the Crossing the Quality Chasm report by the Institute of Medicine [1]. The logic is simple: how can a patient be the source of control for their healthcare if they don't have the necessary information? “Have no secrets. Make all information flow freely so that anyone involved in the system, including patients and families, can make informed choices and know at any time whatever facts could be relevant to a patient's decision making.” (IOM [1], pp. 79–80). The conception of transparency in the IOM report was that doctors or other health providers would share the information that the patient would need to be able to participate in making decisions about their care. The question of how health professionals would determine what information patients needed in order to contribute to the decisions about their care was not fully worked out. The rule, as articulated in the report, was clearly presented as an ideal rather than as a protocol that could be implemented by any practice that chose to follow it.

The Quality Chasm report was as much focused on transparency concerning the details of the functioning of a health system as it was about the transparency that

describes a patient's access to his or her medical information. If the patient is going to be the source of control, they need all the information necessary to choose well who will provide their care. Good choices make for informed "consumers" and stronger relationships. The report points out that the information about medical errors that could come from institutional transparency could help in improving patient safety and in lowering rather than raising litigation against health settings. Over time, elements of this sort of transparency have become more common. A patient can now access information about a doctor and their record with the state medical board. Medicare has a system of grading hospitals, nursing homes, and other healthcare settings, and some rating surveys include measures of patient satisfaction in the data used to determine a site's grade. There is also a movement to try to compel transparency about charges for specific types of care or specific tests in various settings. While a determined and knowledgeable consumer can get a lot of information for making comparisons, at this point comparison of hospitals and other health settings across a standardized meaningful set of measures is not easy or intuitive for most people. The data that is expected to be shared is often not the data on which patients make decisions in choosing care providers, and the scarcity of resources in many areas makes the promise of informed choice irrelevant.

The Quality Chasm report lists two benefits that can come from a patient being able to see their own health record. Firstly, it assumes that a patient might see details of their medical history that were incorrect or incomplete and be able to correct any errors that the record contained. This is seen as a way to increase patient safety. Secondly, the report predicts that patients would be aided in understanding their treatment plan and be reminded toward better adherence to their medical regimen. When the report considers what other sorts of information a patient would see if they had access to their medical information, it lists results of laboratory tests, medications being taken, and the correct doses. This is seen as an improvement in the communication with the patient by the doctor and the health system.

### 7.3 Opening the Record

At about the same time that the Quality Chasm report was coming together, a meeting took place as part of the Salzburg Global Seminar (SGS) in Austria. The SGS is a nonprofit organization that sponsors multi-year programs that convene current and future leaders from across the globe to work for sustainable change for the common good. Fellows, as they are called, are brought to Schloss Leopoldskron, a grand house/hotel outside of Salzburg at which several scenes of "The Sound of Music" were filmed. In 1998, a meeting about the role of transparency in the doctor-patient relationship was convened there. This was by no means the first place that the patient having access to their records was discussed [5], but it was likely the first time that the idea was vetted before a group of such influential medical leaders. At that meeting the idea offered was of an Internet-based patient record that was accessible to both patient and clinician. The record could be written by both the clinician and

the patient. Patients would be able to add to the record to correct information, to track and explicate problems, to prioritize needs, and to make suggestions for diagnoses or treatment plans [6]. There would be ways for patients to keep track of their own adherence to their medical regimens and for health clinicians to provide reminders. The medical record would be linked to patient education materials about the specific illnesses or problems of each patient. Patients could review transcripts of their visits and offer anecdotal feedback through secure email systems. The description at that time was that patients would have “nearly complete” access to their information, though it did not say on what basis some information would be held back. All information would be confidential, held within the medical system on one hand and the group with whom the patient chose to share information on the other. The vision articulated at the Salzburg gathering was published in the medical literature in 2001 [7].

In 2010, another meeting of the same project occurred in the same venue. This program presented the evolution of the idea and what had been achieved in the time since 1998. At that time, Dr. Tom Delbanco, a central player in the drive toward transparency of patient records, reviewed the design of an early pilot program called “OpenNotes” [8, 9]. OpenNotes is a system for allowing patients easy access to the notes of their medical visits written by their doctors. It is portrayed as a movement rather than a specific software program ([www.OpenNotes.org](http://www.OpenNotes.org)). Multiple vendors of EHRs offer or are developing the capability for open notes.

The pilot test of open notes was conducted in adult primary care practices of three health systems, an urban academic medical center in Boston, a rural health system in Pennsylvania, and an inner-city health system in Seattle serving indigent patients. All three systems had or were just implementing electronic patient portals through which patients could access test results, medication lists, appointment schedules, and exchange secure messages with their doctors. Doctors were offered the possibility of their patients being able to read their own visit notes for 1 year with the option to continue with the service after the year was over if they wanted to. Participation by PCPs was voluntary, and the PCPs who declined to participate and their patients became the control group. One hundred and fourteen chose to participate and 140 declined. The patients invited to join the project were patients of the participating doctors who had accounts on the patient portal. Doctors could remove patients from the invitation list if they felt there might be harm caused by their having this access. The participating doctors overall removed about 5% of the eligible patients, with the majority of these designated by doctors whose patient panels included a high percentage of patients with serious mental illness or substance abuse diagnoses.

Participating and nonparticipating doctors and their designated patients were surveyed ahead of implementation to see what they expected from the opportunity for open notes. Seventy to 80% of the participating doctors across the three sites thought OpenNotes was a good idea and expected it would help patients maintain or improve their health. A range of 20–30% of the nonparticipating doctors agreed that it might help patients with self-management. Over 90% of patients cared for by participating and nonparticipating doctors thought it was a good idea. About 50% of

participating doctors thought that it could cause patients confusion or worry, and about 90% of the nonparticipating doctors shared this concern. About 15% of patients thought that might be possible.

At the end of the year, the patients experience with OpenNotes exceeded the expectations of even the most optimistic proponents. Over 80% had read at least one note. They reported that reading their notes made them feel more in control (77–87%, depending on the setting) and improved their medication adherence (60–78%). Some had privacy concerns (26–36%), but about as many took the opportunity to share their medical information with family and other health advisors (20–42%). The nonparticipating doctors' prediction that patients would face increased confusion or worry didn't materialize. Increased worry or confusion was reported by 0–8%. Doctors' fears that visits would be longer did not happen (reported by 0–5% of doctors), and increases in time answering questions outside of visit also rarely occurred (0–8%). About 60% of patients, having had a taste of transparency going in one direction, wished that they could put comments about their doctors' notes in the record. At the end of the year, 99% of patients wanted to continue with open notes, and no doctors dropped out of the program [10].

Since that pilot, the OpenNotes approach has spread among healthcare's leading centers. These centers have added capabilities so that in many settings, other members of the healthcare team who are enfranchised to write in a patient's record can expect that their notes will be read as well. In 2015, there were 85,000 patients who had access to open notes [11]. In June of 2018, that number was 22.7 million (OpenNotes.org). The general experience of doctors, that open notes improves care with little increase in the demands on them, except for the few who report spending a bit more time in writing their notes, tends to make it hard for sceptics who have not tried it to make a convincing case. The overwhelming opinion of patients that open notes is a good thing, both before they get access and after they have it, has made having this capability an important marketing point for health systems that are early adopters.

## 7.4 Open Notes for Multiply-Disadvantaged Patients

We have been particularly concerned with how transparency can be a core element in building a bridge to partnership with multiply-disadvantaged patients. The designers of the open notes pilot were concerned about the effect it would have on patients with low education and low health literacy, especially if they had complex health needs. Wouldn't these patients be put off by complex medical terminology or by hearing what their doctors said about them? In the initial analysis, the research team expressed surprise to find that these patients were just as enthusiastic about the process as more educated patients who were healthier [10].

A later study, focusing specifically on three groups, less educated patients, non-white patients, and sicker patients, highlighted the importance of open notes and transparency in building the bridge to partnership we have been looking for [12].

There was likely to have been substantial overlap in these groups, though that was not addressed in the account of the study. Of the patients responding to the survey, 74% of patients with a high school degree or less education, 71% of African American patients, 70% of Hispanic/Latino patients, and 66% of patients with the poorest self-reported health said that access to their doctors' notes was extremely important in helping them to be informed about their care and to understand their doctor's thought processes. These patients had significantly higher rates of placing the highest value on open notes compared to their more advantaged counterparts in the study. Patients with low education levels were nearly three times as likely as better educated patients to rate open notes as extremely important to help them engage in care. Nonwhite patients were twice as likely as whites to rate open notes as extremely important. Patients with the poorest self-reported health were as or more likely than healthier patients to pick the “extremely important” rating [12].

When we discussed the multiply-disadvantaged patients (Chap. 5), those sometimes identified as complex, sometimes as having lower socioeconomic status and low education, and sometimes as having endured traumatic experiences, we found that many reported experiences with healthcare services that they found to be demeaning or to have endured shoddy care which they attributed to their low social status. We found that doctors sometimes give these patients less patient-centered care because they doubt the patients' abilities to understand the complexity of full descriptions of their conditions and treatments. Doctors may take the lower rates of adherence by these patients to be indications of their difficulties in understanding their health problems and of their need for a more directive rather than a partnering approach. We found that multiply-disadvantaged patients often are focused on the asymmetry of education, income, and power in their relationships with doctors. Trust is very difficult. Any move on the part of the doctor to be personable, to show caring, or to address difficulties that come up in the relationship is likely to be noticed and appreciated. It appears that when a doctor offers open notes, it is taken as just such a move.

The highlighted patients in this study [12] used open notes to help understand their care. They could go back to the notes multiple times and could involve the people in their lives whom they trusted to read them as well. They could be reminded about how to care for their conditions without needing to be directed. They could understand their doctors' thought processes, creating understanding of why their doctors asked the questions or made the suggestions that they did. They reported improved trust and improved adherence as a result.

The researchers ultimately suggested that access to the doctor's notes in itself may strengthen the doctor-patient relationship for these patients. They go on to suggest that doctors and other health professionals should be aware of the value of open notes for improving communication and trust. They offer recommendations for how health professionals can consciously use this tool to build engagement. They suggest that professionals authoring notes try to use clear language. In addition to improving patients' understanding of their conditions and treatments, that would allow clinicians to clearly articulate their understanding of the patient's concerns

and values. Of course, to do that clinicians would need to be conscious of clearly ascertaining what the patient's concerns and values are. If clinicians take this advice, the fact of open notes could be impacting both sides of the relationship positively. Finally, they suggest that doctors should avoid using judgmental language in their notes.

## 7.5 Evolving the Role of the EHR

The current stage of open notes is one development in a longer series of attempts to manage the impact of record-keeping technology on the relationships of patients to their health professionals. The electronic health record (EHR) has been both a boon and a bane for doctors and patients. The role of the EHR in the transparency of doctor and patient communication up to this time has been largely a bane. Using an EHR has tended to structure the doctor's interaction in the direction of protocols and lists rather than in the direction of taking in the patient's story, contributing to the "parallel play" description of the medical interview (citation and chapter). The EHR has tended to absorb greater percentage of the doctor's attention than did paper charts [13], interrupting eye contact with the patient. This important element of nonverbal communication which conveys the HP's interest in the patient has been reduced. Multiply-disadvantaged patients, those most likely to be influenced in their self-management of their chronic illnesses by their perception of their doctors caring about them, are likely to be the most sensitive to the loss of the doctor's attention, interpreting it as relating to their relative importance to the doctor. Less eye contact and direct facing of the patient by the doctor have been correlated with less patient disclosure [14]. Should these patients believe that the doctor pays more attention to the computer during their visits compared to visits with more advantaged patients, they are not alone. One survey found that patients who were Asian, Latino, and non-English speaking or who had not graduated from high school were more likely than other patients to report that their doctor spent more than half of their visits looking at the computer screen [15].

It is probably fair to say that the period in which the EHR has functioned as a boon in the HP-patient relationship is in its infancy. The first step in transparency in relation to the EHR has involved attempts to allow the patient to see the same screen that the HP is looking at in an encounter. This has been attempted by rearranging exam rooms so that the patient and the doctor sit closer side by side, adding a second screen that can be faced toward the patient, or projecting the record on one large screen that is easily viewed by everyone in the room [16]. The introduction of a new person to manage data entry and data access from the EHR has allowed doctors to break their tether to the computer screen altogether. Each of these adaptations has been generally well received by patients who are glad for almost any step in the movement toward having more access to their own data [17].

## 7.6 Changing Language and Content to Build Partnership

Using open notes as a regular communication channel with patients by including information which, whether stated in the visit or not, is designed to improve the relationship between the patient and members of their healthcare team could be revolutionary. To make open notes a pathway to partnership, the early innovators are recommending three changes in how information is captured and displayed: first, a reconsideration of the way information is organized is needed to make current lists and test values more accessible; second, a regular place for information supplied by patients about their experiences of their illness and their values and preferences for their care; and finally, the usual language used by health professionals in describing their patients needs to evolve from a “neutral” recounting to a language that is experienced by the patient as coming from the commitment to them. The early innovators face the following question: if we are trying patient-centered care as a pathway to partnership by eliciting the patient’s concerns and preferences, by hearing the patient’s story of the reason for the visit without offering early interruptions, by addressing the emotional content and significance of what the patient is saying, or by expressing empathy or support for the patient’s struggles, should not that information be as much a part of the record of the visit as the history of the present illness, the review of systems, the assessment of the doctor, and the plan?

The organization of information in most EHRs becomes a greater problem for communication when patients can view their records. EHRs are particularly good at capturing medical data for minor acute medical problems. For more complex problems such as multiple or chronic complaints, the common ways they organize information are of less help [18]. Patients often have test results presented with the normal range for each test shown, but the purpose for each test or the way a test that is out of the normal range is linked to their current treatment plan is not as clear.

As patients’ preferences in relation to their care become a usual part of their record, one that is available to all health professionals using the record, standard categories reflecting these preferences need to become added to each record or to the records of some designated populations of patients. Chap. 10 goes into this issue in much more detail. It would seem sensible that a rethinking of the categories of information in the standard medical note would be undertaken by a practice or a health system that was implementing open notes. After open notes had been implemented for a while, it would be possible to assemble a group of patients from the practice to help with that redesign.

Gerard et al. [12] point out that open notes seems to add more value to the care of multiply-disadvantaged patients than it does to the care of healthier and more advantaged patients. To keep the language of the note from being an impediment, they advise clinicians not to use judgmental language in their notes. This might be a beginning, though advising doctors not to use judgmental language probably is not the best place to start. In 20 years of reading doctors’ notes about patients that I shared with them, I cannot remember a single note that struck me as overtly judgmental. They were written in the ostensibly neutral terms of professional medical

language. That language is full of terms such as “non-compliant,” “obese,” “drug user,” “low cognitive ability,” and “personality disorder” that are acceptable professional descriptions. While a patient reading that language might very well experience the note as judgmental, I believe that telling the doctor not to use judgmental language would seem an unnecessary instruction to almost all. They were writing in a way they were taught, a way that was designed to be free of any judgments other than medical ones. Why would professional language seem judgmental to patients if it is not meant that way by clinicians? Consider what we have said about the elements of a doctor-patient relationship that multiply-disadvantaged patients report to be helpful to them: the doctor is personable, the doctor seems to care, and the doctor tries to recognize and address times when the patient is withdrawn or alienated. Professional language, in contrast, is purposefully impersonal, leaves out the emotional experience of the author, and, if it comments on the relationship at all, focuses on patient’s behavior in the visit rather than trying to report the patient’s experience of the visit. [OpenNotes.org](https://www.opennotes.org), a great source of suggestions for implementation guidance for open notes, suggests that clinicians modify their note writing:

- **Difficult conversations:** If it’s important enough to put in the note, it’s important enough to talk about. Knowing that “you’re on the same page” can improve trust and the relationship.
- **Avoid jargon, acronym, and abbreviations:** Avoid jargon and abbreviations, especially those that might easily be misinterpreted by your patients (e.g., “SOB” or “patient denies”). Briefly define or simplify medical terms (short of breath, rather than dyspneic).
- **Provide a balanced perspective:** For mental health issues in particular, describe the patient’s strengths and achievements along with documenting clinical problems. This can help the patient gain a broader context within which to consider illness and tackle difficult behavioral changes ([OpenNotes.org](https://www.opennotes.org), downloaded 1/22/19).

Changing any language in the note that documents a visit, even if it will help engage the patient, has to be done very carefully. Medical notes serve multiple purposes for multiple constituencies. The note must remind the clinician and other team members in the practice of what is known about the patient and what has been done in their care so far. It must briefly give new clinicians or team members enough information to provide safe and effective care if they have to take over some aspect of the patient’s treatment. It must be a true record of what was done for the sake of quality monitoring, whether that monitoring is by the practice itself or by outside regulators or payers. The purpose of documenting the visit for the information of the patient and for enhancing the clinician-patient relationship cannot undercut any of the other purposes which the note now serves.

With these requirements in mind, we can begin the process of making the note more communicative and engaging for patients. The first step is to make the note acknowledge a relationship. People in a relationship call each other by their names. Whether the patient, Mary Smith, is called “Mary,” “Ms. Smith,” or “Mrs. Smith,” using her name is a start. (Asking a patient what they would want their doctor or

team members to call them should be part of the initial information collected in any practice.) The note would document the information the patient brought to the visit using narrative conventions, not by being longer, but by being more personal. Instead of saying “patient reported ...,” the note might say “Mary told me ...” or “John described ...” or “Mrs. Gonzalez explained.” “Pt denied current ETOH use” can become “John says he no longer drinks alcohol.” “MS, 47 yo F., with DM, obesity, and depression,” becomes “Mary Smith is a 47-year-old woman who came today for help in coping with her diabetes, her weight (BMI 32), and her depression.” The notes are equally communicative to other health professionals in their reworded forms and significantly more comfortably communicative with the patient that way.

Consider the way that professional language sometimes implicitly describes patients as passive receivers of both illnesses and treatments rather than as agents in their own lives. Look at any problem list for an example of this phenomenon. The characterization of patients as people who make decisions in their own lives can be helpful as we move into areas that can seem more challenging to document. Suppose the patient let the doctor know that he had not taken the medication that the doctor prescribed. A note that was not intended as a communication to the patient might say, “patient reported that he has not been compliant with his long-term asthma control medication.” That phrasing connotes a person who is not doing as they were instructed to do, a person who is not cooperating with the treatment the clinician is providing to them. A note that characterized the patient as an agent in his own health might say, “John let me know that at this time, he has decided against taking his long-term asthma control medication.” In a relationship, people don’t always agree. In a successful relationship, disagreeing does not imply an end to working together. Phrasing the note in the second way leaves open the space for better understanding of what was behind each member’s point of view, both by being clearer about why the doctor recommended a long-term asthma control medication and by clarifying why the patient would choose not to follow that advice. Clarification of the patient’s perspective can open up chances for improved care by helping isolate the information that is missing from the discussion. It also highlights the patient’s autonomy in making decisions about their health. Honoring the patient’s autonomy is a core element of the Quality Chasm report and of the spirit of motivational interviewing, the evidence-based approach to helping patients make and keep good decisions about their health [19] discussed in Chap. 4.

Focusing on the patient as an agent in their own health tends to emphasize what they are doing for their health, rather than what they are not doing. Instead of noticing that the patient did not do the entire activity that was recommended, it tends to bring out the parts of the activity that they did accomplish. Imagine that a patient, John, has been prescribed a medication to be taken three times a day. If he is consistently missing his mid-day dose, the note might say that so far he has been able to take it two times a day. If the patient is late for an appointment, one way to describe that would be, “the visit was shortened today because the patient arrived late.” Another way to describe it would be, “Mary was determined not to miss the visit today and came even though she was running behind schedule.” Documenting the

**Table 7.1** Change your language to engage and activate your patient

Negative/passive words	Positive/active words
Suffers from	Struggles with, copes with
Refused to take	Decided against
Didn't keep the apt	Was unable to be here
Was non-compliant with	Had not seen value of
Arrived late	Was determined not to miss
Work together to extend the list	

patient as an agent in their own health and noting what they are doing rather than what they are not doing is new to most people who write medical notes. When members of a healthcare team try creating similar examples of a different way of writing (while still making sure that the facts that might be needed later are not obscured), it often elicits smiles. It can become like a game. See Table 7.1.

The practice above is often called “reframing” and sometimes called “recontextualizing.” It means that a description, observation, or idea is put within a different contextual background or “frame” and therefore changes meaning. This can involve changing the pattern in which an act is portrayed. “She is always resistant and now she has told me she doesn’t want to follow my suggestions again” is one way of characterizing a person’s pattern of behavior. Another is “she is always clear about what she is going and not going to do, unlike many of my patients who agree and then don’t follow through. I appreciate her honesty.” Sometimes people who are just learning to use reframing experience it as dishonest. “If I feel she is resistant, isn’t it lying to say that she is honest?” The transitional step for those people is to consider what is most effective. It is, after all, our most fundamental duty to help the patient, rather than to express what we feel at the time. The Centers for Disease Control and Prevention recommends reframing when it recommends that instructions about the dangers of unsafe sexual practices that are given to HIV-positive patients be framed as being for the protection of their own health, even though the protection of their potential sexual partners is extremely important to health professionals as well. Framing the advice as protecting the patient’s health, which is also factually true, has been shown to be more likely to influence patients toward safer sexual practices than a focus on the partner [20]. Health professionals tend to get more comfortable with using reframing when they see the positive impact on their relationships with their patients and when they see the effectiveness that is fostered by this better relationship.

Using clear language, making the note more personal by using patients’ names, describing patients as agents in their healthcare rather than passive recipients, and highlighting what a patient is doing rather than what they are not doing for their health can create a note that is designed to improve partnership with multiply-disadvantaged patients and probably would improve the relationship with most patients. None of this means, however, that the medical content of the note should be watered down or changed. Some medical terms can be replaced by terms used by laymen, but many cannot. Medical language is more specific. To convey the same specificity of description of a particular condition in layman’s language in many cases requires many more words than in medical terminology. The changes in lan-

guage that highlight the patients’ agency and strengths are likely more important than translating all of the medical language and abbreviations into a laymen’s vocabulary. If the studies we have cited are credible, it seems that many patients are willing to make the effort to do some translating.

Behavioral health notes raise special issues in the open notes conversation, because of the history of special status for mental health and substance abuse notes and the culture of protecting notes in mental health settings. The practice of sharing notes with the patient whose care they document is a different issue than the practice of sharing notes among professionals. Sharing notes among professionals is a long discussion in itself. Suffice it to say that where behavioral healthcare is part of primary care or another medical setting, behavioral health progress notes in the medical record can and should be shared with the healthcare team, and any psychotherapy notes that cannot be shared should not be part of the medical or billing record ([www.hhs.gov](http://www.hhs.gov), Health Information Privacy).

Since 2006, all patients have had the right to a copy of their medical records if they ask for them, though some health settings have made the process inconvenient. The fact that so few have exercised that right in the past means that while all people who document in the medical record should have been told to write as if the patient was going to read it, few have had this as a consideration as they were charting. I think that if team members were a part of a workshop on reframing in chart notes, they might or might not be interested in practicing this different way of writing, but nothing in their routine would make it necessary. The skills would fade over time rather than improve. Because many medical practices will not have open notes for some time, I suggest that everyone who meets regularly with patients and then writes in the chart about the meeting tries a practice I have found to be the most helpful clinical routine I have ever used: reading back the notes of the last meeting at the beginning of the next.

Reading the note from the last visit takes very little time at the beginning of a new visit, especially for follow-ups of any sort, whether medical, behavioral health, care management, or coaching, which are not occurring because of a new complaint or concern. It focuses both the HP and the patient on the topics and brief content of their previous conversation. I found this helpful in follow-up visits because the patient often had lost the thread of our work together since the last time we talked. Instead of asking people whether they remembered what we talked about last time, the reading of the note became part of the routine of the visit. This means that the reframes or emphases that I thought would be useful at the end of the last visit are immediately made available to the patient, with the invitation in every case that they correct whatever I got wrong. This almost never happened. One of my favorite moments in my work in primary care behavioral health was the time when patients came for their second meeting with me. My reading of the note, as if that were a sensible routine practice, in almost every case was positively received by the patient. I usually remarked that I wanted them to correct any mistakes in the notes because that is the information that was shared with colleagues on the team. Patient’s rarely asked for changes and then only for factual details (I have three brothers, not two)

rather than in interpretations or emphases. Patient's often said that they wished other people who provided care did the same.

It is something of an aside here, but I am aware that my behavioral health colleagues may well be protesting that writing a brief note including positive reframing of the patient as an agent in their own healthcare that will be read to the patient is all well and good, but what about the requirements that mental health billing regulations have for documentation to support a fee-for-service bill for the interaction? While I would like to answer by appealing to the day when payment transformation puts all payment, formerly medical and formerly mental health, into one payment stream and pays a set price for the full care of the patient to the primary care practice and the health system within which it resides, that day may be a long way off for many of us. In the meantime, I offer the note format that I found made the practice of writing as well as reading the note simple yet defensible to auditors. (I cannot guarantee that this note format fits billing requirements in every location, so it should be vetted locally by anyone who is considering adopting it.) Together with the compliance office<sup>1</sup> of our health system, I created a form designed to meet billing documentation requirements and to be easy to read back to patients. I would read the text back to the patient, the same text that would be read by my colleagues, about my work with the patient. The form (see [Appendix](#)) included information delivered using check boxes substantiating the billing. I was able to fill out the form in a Word document in about 5 minutes and copy and paste it into the EHR.

From the mental health world has come an innovation in note sharing that may at some point be applied commonly in some medical settings, collaborative documentation [21]. This is a practice in which the clinician and the patient co-construct the record in the process of the conversation that the record documents. It has been developed in the treatment of people with serious mental illness whose engagement in care is often hard to sustain. The vast majority also have multiple chronic illnesses and can reasonably be called “complex.” The rate of trauma histories for these patients is very high. The issues of stigma, power differentials, the need for peer support, and the need for the patient to be in the lead are central to creating successful treatment environments. In collaborative documentation the creation of the record becomes a cooperative project that involves patients and professionals discussing what will be written in the record at the end of each visit. This practice has led to increased rates of patients keeping appointments and adhering to medication [21]. Similar involvement of patients in creation of their records is done by some individual medical providers, but currently I don't find evidence that there is any broad push for adding this process into the hustle and bustle of primary care practices. Other team members, such as BHCs, care managers, navigators, or health coaches, might well consider it. Creating the time for the conversation is an impor-

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<sup>1</sup>Hospital systems commonly have a compliance office made up of staff members, some of whom are lawyers, who do internal monitoring of records and practices so that when external reviewers or auditors arrive, the institution will not have to give back payments that are judged to have been inappropriately obtained because the existing documentation doesn't support them.

tant barrier, though in the evolution of alternative team routines and scheduling schemes (see Chap. 2; [22]), it may become possible. At that point the record becomes a true record of a relationship created by the relationship.

## 7.7 Speaking As Well as Writing

There are two ways that health professionals use their language to describe patients, writing and speaking. Just as the medical record has been a domain to which patients have had little or no access in the past, the conversations about patients, particularly among members of the healthcare team, is an arena from which patients are usually excluded. When the healthcare team is organized like a squad (see Chap. 2), i.e., staff members supporting the work of the doctor, who is the main source of expertise in the treatment, the conversation in the hall about the patient is usually fairly mundane. It consists of brief exchanges designed to coordinate the various tasks that go into making up a patient visit. Telling a patient who feels particularly vulnerable in medical visits that most conversations are brief and instrumental, rather than evaluating or judging the patient, probably would not be comforting. Observing conversations in the hall, especially if there is any exchange of smiles or if someone laughs, can increase the patients’ concern that people are talking about them in less than complementary ways.

When the healthcare team expands to include a new expertise set, such as when a behavioral health clinician joins the team, the conversations in the hall tend to become longer and more detailed. One of the most common ways that a behavioral health clinician can be added to the treatment team for a particular patient is through a process called a “warm handoff.” The doctor introduces the behavioral health clinician to the patient during the patient’s medical visit. The behavioral health clinician can speak to the patient long enough to begin to understand the patient’s view of the concern that the doctor identified and to attempt to make an engagement with the patient to work on the concern. Sometimes the BHC offers brief interventions as part of the warm handoff process. A warm handoff, with its face-to-face introduction, is much more effective at building engagement between the BHC and the patient than a simple referral by the doctor to a BHC whom the patient has never met. In an informal study in one health center, the new BHC kept a record of all his scheduled first appointments and whether or not the appointment was kept. He found that if he had been introduced to the patient by the doctor previously to the scheduled appointment (warm handoff), the chance that the patient kept the first scheduled appointment was almost double the chance that the appointment would be kept if the doctor had simply requested that the appointment for the patient be scheduled with the BHC without an in-person introduction [23].

The warm handoff is much more effective for engagement, but it can be time-consuming for doctors, particularly if they have to have a conversation with the

behavioral health clinician about the medical and behavioral situation of the patient in the hall before the introduction. That tends to make the in-person introduction to the patient in the exam room feel redundant to the professionals who just spoke in the hall. On the other hand, if the introduction is done in the exam room with the patient with no orientation of the BHC to the patient's situation, it can make the conversation with the patient after the exit of the physician awkward. When the introduction and orientation of the BHC and patient is too brief, it leaves the purpose of their conversation unclear and makes their engagement more difficult. The patient may be left not sure what the new team member knows about his/her situation and uneasy about where to start. The BHC doesn't know how much of the information that the doctor shared in the hall is understood or accepted by the patient.

The more efficient solution is to have both conversations, the orientation of the BHC to the patient's situation and the introduction of the BHC and the patient, in the exam room with the patient. This is transparency in the conversation about the patient. The same skills that were discussed above for writing engaging medical notes are useful in creating engaging conversations with and about the patient. Using the patient's name, sharing the difficulty he or she is facing, and highlighting what the doctor and patient have already done can set the task for the next team member. Rephrasing descriptions to characterize a patient as an agent in his or her own health rather than as a passive receiver of illnesses or treatments forms the basis of the change. As with writing, the more one speaks with other team members in front of the patient, the easier and more natural it becomes.

## 7.8 Passing the Relationship

One of the challenges of a healthcare team is the inevitability that the patient will have a different sort of relationship with different members of the team, depending on their role and on how well they relate to the patient in that role. In most cases, the patient's relationship with the doctor will be the most important to the patient. It is the doctor's expertise that brings the patient for care. Occasionally a patient's relationship will be stronger with the team member who spends significantly more time with them, such as a care manager. And sometimes a patient will form the closest bond with a team member whom the patient finds most approachable, for reasons such as being of similar genders, cultures, language skills, age, or personality. If the team is going to function efficiently, it helps to have a method for leveraging the positive connection of one team member to quickly build a trusting relationship with the patient for another.

Speaking in the presences of the patient can be the basis for a thoughtful routine for the introduction of a team member who is new to the patient, made by the team member who has the closest connection. This is most effectively done by combining the conversation that orients the new team member to working with the patient and the conversation that orients the patient to working with the new team member. It is a conversation between the patient (and family members or others who are part of

the patient’s care), the current team member, and the new team member. When done well, this process is built on the foundational skills of talking in front of the patient that are described above. We will call this “open clinical discussion” in primary care.

Open clinical discussion as we are using the team was created originally to help doctors add the BHC to the team, though it can be used for other relationships as well. It is not meant to be the only way of passing of the relationship, but it is an example of elements that can make the process more efficient. When passing the relationship, consider using the mnemonic of SSRI<sup>2</sup> to organize the introduction. It is designed to help doctors, or the team member with the current relationship with the patient, conduct this process smoothly and efficiently once they and the patient have agreed that something additional in the care could be needed.

The first **S.** is for **Situation**. The doctor (or team member with the closest relationship) says to the patient and the BH clinician (or newly involved team member) what *situation* in the patient’s current care makes him or her want to recommend adding the BH clinician to the treatment team. The process starts with the patient’s need that the new team member will address. The current team member can try to be aware of the patient’s understanding of their need and to use the patient’s terminology, as well as the team member’s terminology to describe it.

The second **S.** is **Skill Set**. The doctor describes to the patient the *skill set* (as opposed to the discipline) of the BH clinician that makes him or her the person that the doctor wants to add to the treatment team. Whatever the skill set of the new team member, it should be phrased to be a fit for the patient’s need that was mentioned in the Situation statement.

The **R.** stands for **Relationship**. At this point the doctor says what *relationship* the work between the BH clinician and the patient will have to the overall treatment that he or she and the patient have been conducting. Remember, this isn’t a new treatment; it is a new aspect of the patient’s current care. In any situation, the new team member is augmenting the existing care. The “relationship” part of the statement helps a patient to know how this fits together.

The final **I.** is for **Indicators**. The doctor says to the BH clinician and the patient what would *indicate* that the addition of the BH clinician’s expertise and intervention had been successful. If the care, including the efforts by the patient, that this new team member can offer does what we hope, what improvements will the patient and the team start to see occurring?

Below is an example of the elements of the SSRI designed to add a BH clinician to the care of a patient in a way that allows the patient and BH clinician to begin

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<sup>2</sup>The ideas about passing the relationship were first published in Blount, A. (2018). It takes a team. S. Gold and L. Green (Eds.) *Your Patients are Waiting: Integrating Behavioral Health for the Primary Care Physician*. Springer Publishing, New York.

working quickly and smoothly to address the goal(s) identified by the doctor and the patient. Notice that the doctor doesn't specify what sort of intervention the BH clinician will use nor how many contacts between the BH clinician and the patient will be involved. Those are dependent on the expertise of the BH clinician and the connection that develops between clinician and patient.

On paper this may seem like a complex process. Try reading the examples out loud. You get a complete statement that would require less time than is usually taken for either the hall discussion or the in-room introduction.

- S:** Bob Lawrence (patient), this is Joseph Gonzalez (BHC). Bob reports he is experiencing the early stages of a recurrence of his depression. One way in the past that he has shown that he was having a recurrence was he stopped taking his diabetes medication. Bob let me know today that he has gotten a little unreliable at taking the medicine lately and that he thinks about stopping it fairly often.
- S:** Mr. Gonzalez has a lot of experience helping people keep minor recurrences of depression from developing into major episodes and helping them keep the parts of their lives that they worked hard to achieve from sliding backward.
- R:** Bob, I am hoping that while working with Mr. Gonzalez, you can get back on track fairly quickly. I would like to get an update from the two of you in 3 weeks so that we can restart antidepressant medication if that is indicated.
- I:** Bob and I have discussed his situation, and we agree that if he is able to get through a mild recurrence of his depression without losing traction in his health, his work, or his social life, meaning his diabetes stays managed and doesn't cause him to miss work, it will mean that the progress he has made is getting more reliable. I think that could give him confidence about planning for his future, something that up to now he hasn't quite been able to do.

Notice that the aspect of the BH clinician's skill set that is most relevant to the patient's situation is what the doctor stresses. In the case above, Mr. Gonzalez is a skilled BH generalist, experienced at working with the mental health, substance abuse, and health behavior needs of adults and children. But it is not his skills with substance abuse care, or health behavior change that make him someone that Bob Lawrence would want to work with, it is his skill at helping a patient manage the impact of a depression recurrence. That is the skill set that is highlighted. In the early stages of their work together, Mr. Gonzales will tell the patient his discipline that he is a licensed clinical social worker, but that will be as part of the further introduction of himself and the process.

When it is possible with schedules, it is also effective to have a "report back" to the doctor by the BH clinician and the patient as their work draws to a close. It orients the doctor briefly to the specifics of what was useful in their work together. It allows the BH clinician to say complimentary things about the patient and sometimes vice versa. It passes the role of clinician regarding behavioral aspects of the patient's care back to the doctor and enfranchises him or her to remind the

patient of the skills that they learned in working with the BH clinician when those skills could be useful in the future. This is most easily done if the BHC “looks in” on one of the patient’s regular visits with his doctor.

Sometimes passing the relationship requires an aspect of the current relationship to be spelled out a bit so the need for the involvement of the next team member is clear. It helps to say a sentence or two about the work that has been going on in the current relationship and then to say a sentence or two about the challenge that has come up and why the challenge needs to be addressed. (Below, the doctor is introducing a care manager.)

**S:** Mary Smith (patient), this is Octavia Melendez (care manager). Octavia, Mary and I have been working to try to keep her diabetes under control. Since her last visit, the friend she was staying with has had to ask her and her son to leave because the landlord won’t allow extra people. They are staying in a shelter, and everything is so much harder now. She has a hard time getting her medicine. She tries to keep her mood up, but she has so little privacy that anybody would find it hard. It is easy to feel hopeless. There are a lot of folks in the shelter who are using drugs, so she is worried about her sobriety.

**S:** Octavia is our team member who is best at solving problems, like helping people find a place to live or helping them get the additional services they need.

**R:** The last time Mary had secure housing, her son was doing well in school, she felt healthier, she was getting some exercise, and she was taking her medication. She was more confident in her sobriety, and she was able to go to the vocational training program at the community center.

**I:** With Mary’s connections to her family and friends, and with Octavia’s knowledge of resources, I am hoping that fairly quickly Mary will begin to feel some hope about finding stable housing and that in not too long a time the two of you can find a stable place for Mary to stay.

Here the doctor is introducing a medical assistant who will teach the patient to use a spacer with her asthma inhaler.

**S:** Elena Medina (patient), this is Louis Wallace (medical assistant).

Elena has been having trouble with her breathing lately, even though she is taking her asthma medication on time. She has had to go to the emergency room twice because she got so worried that she couldn’t get her breath. I think that having a spacer with her inhaler could make a big difference for her in how much the medication helps her.

**S:** Elena, Louis is one of our team members who is very good at teaching people to use their health equipment, like an inhaler. Learning to use a spacer can take a bit of practice. Louis is skilled at teaching how it is done.

**R:** So, Louis, please take the time you need until Elena is confident she knows how to use the spacer correctly.

**I:** I think that if Elena was more confident that her spacer and her medicine were going to help her every time she needs help, she could feel less anxious about

how her day was going to go, and that might even save her a few times of needing to use her inhaler.

The SSRI conversation can start the practice of discussing patients' situations between team members with the patient participating on a broader basis. It allows for other members of the team to see examples of what such a conversation looks like. It is much easier to have conversations about the care of patients in their presence than most team members imagine.

No one needs to change the facts that are discussed, though it helps to have a change in some of the types of language in which the facts are couched (Table 7.1).

## 7.9 Implementation

I suggest that if team members are uncomfortable with the idea of open clinical discussions, they be given the option of having conversations about the patient separately but that some of the weekly team meeting time be given to discussing how the same information could be passed in open clinical discussion. As a way to build the skills of team members in having conversations in front of patients, the team can practice adding to the list in Table 7.1. At first, they are likely to experience the process as humorous and forced. It is not what they “really think” about the patients. If they imagine or role play using these terms in clinical practice, the impact begins to become clear. When the experience of the patient is factored into the exercise, and the difference in the behavior that the patient is likely to exhibit begins to become apparent, people begin to see this as an exercise designed to make their work lives much easier. They begin to feel the descriptions take on more authenticity.

As team members get more comfortable in having conversations in the presence of patients, as their characterizations become more active and positive than they have used in the past, they tend to develop greater comfort and skill at speaking with patients generally. This is not something to force, but it is something worth cultivating and nurturing.

## 7.10 Summary

We are building a scaffold with the practices of transparency. Open notes, reading notes from the previous visit, and open clinical discussions underlie and support the other elements involved in making partnership work, in making the routines of primary care practice with multiply-disadvantaged patients empowering, activating, and mutual. We will go back through the ways of using the note, ways of speaking in front of the patient, and ways of constructing core documents and

practices of care mutually with the patient, and each time we do it, it should make the processes more resonant for both patients and team members. This multiple-pass approach to describing the method mirrors a realistic approach to learning the method. Each pass adds a new layer of new techniques on top of an existing structure.

Transparency creates a novel situation for most team members. Openness to new learning is enhanced when people perceive their situation as one that is new to them, yet one in which they want to function successfully. Open notes and open clinical discussions comprise such an example. In a new situation, new rules can be learned without implying that what people did in the old situation was a problem. As people experience multiple iterations of successful actions in the new context, the situation becomes more familiar. It takes less energy for attending to being successful in the contingencies of the new environment, and people have attention freed up for observing less dramatic details. They can learn new small changes that can make a big difference, once they are oriented to the environment as a whole. Transparency is the core structure, the scaffold, of the new environment as a whole.

Next, we can add details of conversations and actions that are designed to foster empowerment of patients. From there, we begin helping patients activate themselves, to generate new behavior or to strengthen old behavior for their own health, as a refinement rather than a major change in approach, attitude, or routine. Finally, initiating and conducting the core assessment and treatment plan, the treatment plan that will be used by every member of the larger health system, in full partnership with the patient and their close network of supporters, is an affirmation of the partnership with the patient.

The preparation for and the implementation of open notes and open clinical discussion can be the first step toward the goal of caring effectively for multiply-disadvantaged patients after the team is in place. This approach to transparency requires new ways of speaking and writing for everyone. The behavioral health clinicians are no more likely than the medical clinicians or other team members to have experience communicating this way. The process of implementing open notes and open clinical discussion, because they are new to everyone and not based on an expertise that is part of the training of any particular discipline, means that learning transparent speaking and writing can be a leveling process for the team. In Chap. 2 we described a process for building the routines of the team that required the doctor to have a conception of the growth of team members and to actively foster that growth. Moving to open notes and open clinical discussion may give team members with more training, such as the doctor, opportunities to learn from and to compliment the skill of other team members in this mutual endeavor. The impact to transparency with patients ultimately can positively impact the working relationships and the transparency within the team delivering the care.

# Appendix

**Ambulatory Service Record:**

Diagnosis	Code	Descriptive Statement
Primary		
Secondary		
Tertiary		

Name, DOB, MRN, Date

- Individ Psychothrp: \_\_\_\_\_mins(20-30)
- Individ Psychothrp: \_\_\_\_\_mins (45-50)
- Family Therapy w pt \_\_\_\_\_mins
- Family Therapy w/o pt \_\_\_\_\_mins
- Init MH Assess & Intrv \_\_\_\_\_mins

- Init. Hlth & Behav Assess (96150) \_\_\_\_\_mins
- Subseq Hlth & Behav Assess (96151) \_\_\_\_\_mins
- Indiv Hlth & Behav Intrv (96152) \_\_\_\_\_mins
- Grp 2+ pts Hth & Behav Intrv (96153) \_\_\_\_\_mins
- Fam Hlth & Behav Intrv w/pt (96154) \_\_\_\_\_mins
- Fam Hlth & Behav Intrv wo/pt (96155) \_\_\_\_\_mins

**Problems from Treatment Plan:**

- Problem #1: \_\_\_\_\_  
 Current Status  No Change  Improved \_\_\_\_\_  Worse \_\_\_\_\_
- Problem 2: \_\_\_\_\_  
 Current Status  No Change  Improved \_\_\_\_\_  Worse \_\_\_\_\_
- Problem 3: \_\_\_\_\_  
 Current Status  No Change  Improved \_\_\_\_\_  Worse \_\_\_\_\_
- Medical and social history documented in medical chart and reviewed before first meeting.  Reviewed limits of confidentiality.

**Other Problems Discussed, Assessment / Additional Comments: (narrative portion of note)**

**Topics covered in visit relating to:**  Problem 1  Problem 2  Problem 3

<p><b>Evaluation &amp; Discussion of Problem(s):</b></p> <input type="checkbox"/> Frequency / Severity / Other Details <input type="checkbox"/> Factor Contributing to Problem, Triggers <input type="checkbox"/> Factors Maintaining Problem, Barriers to Change <input type="checkbox"/> Past Coping Efforts <input type="checkbox"/> Other: _____		<p><b>Cognitive – Behavioral Interventions:</b></p> <input type="checkbox"/> Self-monitoring: _____ <input type="checkbox"/> Stimulus Control: _____ <input type="checkbox"/> Relaxation Training <input type="checkbox"/> Mindfulness / Awareness Skills <input type="checkbox"/> Identification of Dysfunctional Thoughts / Beliefs <input type="checkbox"/> Cognitive Restructuring <input type="checkbox"/> Development of Hierarchy of Treatment Targets <input type="checkbox"/> Systematic Desensitization <input type="checkbox"/> Relapse Prevention <input type="checkbox"/> Application of Skills to Problem Situation / Symptoms <input type="checkbox"/> Other: _____	
<p><b>Treatment Planning, Pt. Education:</b></p> <input type="checkbox"/> Psycho-education re: Problem & Treatment <input type="checkbox"/> Discussion of Treatment Plan & Goals <p><b>Strengths, Foundation for Future Growth:</b></p> <input type="checkbox"/> Determination to Feel Better <input type="checkbox"/> Past Coping Success: _____ <input type="checkbox"/> New Behavior Began: _____ <input type="checkbox"/> Other: _____		<p><b>Additional Treatment Recourses Discussed:</b></p> <input type="checkbox"/> Psychiatric Medications: _____ <input type="checkbox"/> Medical Provider: _____ <input type="checkbox"/> Nutritionist: _____ <input type="checkbox"/> Couples Therapy <input type="checkbox"/> Group Therapy <input type="checkbox"/> Reading Material <input type="checkbox"/> Internet Recourses <input type="checkbox"/> Self-help (AA, NA, DA) <input type="checkbox"/> Other: _____ <input type="checkbox"/> Other: _____ <input type="checkbox"/> Other: _____	
<p><b>Life Style Modification:</b></p> <input type="checkbox"/> Eating Behavior <input type="checkbox"/> Sleep Hygiene <input type="checkbox"/> Management of Stressors <input type="checkbox"/> Physical Activity <input type="checkbox"/> Smoking <input type="checkbox"/> Pleasurble Activs, Self-Care <input type="checkbox"/> Social Support <input type="checkbox"/> Positive Life Goals <input type="checkbox"/> Other: _____		<p><b>Risk Assessment:</b></p> HI/SI <input type="checkbox"/> Y <input type="checkbox"/> N Plans <input type="checkbox"/> Y <input type="checkbox"/> N Means <input type="checkbox"/> Y <input type="checkbox"/> N Active <input type="checkbox"/> Y <input type="checkbox"/> N SA <input type="checkbox"/> Y <input type="checkbox"/> N Agitation <input type="checkbox"/> Y <input type="checkbox"/> N History <input type="checkbox"/> Y <input type="checkbox"/> N	

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