

Disclosure: Providers and Patients

Interactions between providers and patients are central to treatment and prevention of many health conditions. In this interaction, the provider facilitates patients' sharing of personal information—a process studied under the label “disclosure.” Patients share their information face to face, on written or electronic medial forms such as the intake questionnaire, and increasingly in online contexts. This sharing can include, for example, current medications, medical and family health history, and/or past/present symptoms and treatment. Accurate and complete patient disclosure is crucial to diagnosis and treatment, yet more needs to be learned about how to facilitate this sharing efficiently yet thoroughly. Most of the disclosure focus lies within the history-taking segment of a consultation compared with the management-plan portion of the visit. This research generally focuses on patient interactions with physicians, but there are also increasing roles in history-taking for other medical providers, such as nurses or technicians, that provide opportunities to examine how to maximize relevant patient sharing.

Examining patient disclosure requires focus on the relationship beyond the provision of information or diagnosis, recognizing contradictions between content (task) dimensions and affective (relational) dimensions of communication. How these disclosure processes are linked with health outcomes is still not fully understood. Much of the research in this area focuses descriptively on the process of interactions or the effect on patient satisfaction, with less documentation of the effects on long- or short-term outcomes. Many studies have examined established relationships (e.g., rheumatologist or oncologist), but others focus on initial interactions (e.g., first visit with a specialist or internist). This research examines health outcomes such as patient satisfaction, physical and psychological health, medication adherence, quality of life, and initiation of malpractice litigation following medical error.

Disclosure has a long tradition of study in the fields of interpersonal communication, relationships, and social psychology. The provider–patient

relationship is a specific relationship context with power imbalance and patient loss of control that violates norms for disclosure in other relationships and may leave patients feeling particularly vulnerable when sharing. Some argue for increased patient participation, yet this must often be accomplished while one person is sick and the other holds relevant specialized information. Two key features that are not generally a component of provider–patient relations characterize disclosure in most other relationships: reciprocity and withholding negative information early in relationships.

In terms of reciprocity, the nature of the medical interaction requires patients to share personal information while the provider is often sharing no personal information (the patient does receive diagnostic information). This imbalance can lead to patients feeling particularly exposed, yet it is an accepted part of the relationship structure. For example, therapy requires the patient to share in depth, but therapists often reveal little personal information about themselves. It would also be common to know little beyond a surgeon or specialist's medical training. Often patients do not even meet an anesthesiologist or an assistant prior to surgery. This is a relational context in which disclosure (and information sharing generally) is imbalanced because the medical personnel know a great deal about the patient, and patients share personal information in addition to detailed medical information but know little about the provider.

Patients' Management of Information

In terms of withholding negative information, research has established that people generally do not share negative or “risky” information early in a relationship and wait to share this news until they know the other person better and/or have a better sense of how the other person might respond. In the provider–patient interaction, however, patients must share (often in the first interaction) what could be stigmatizing information. If a patient had a prior negative response to sharing sensitive information this may increase caution and make him or her wary of sharing. For example, if a woman shared with her previous gynecologist that she had been raped and the provider responded by changing the topic

and avoiding eye contact, the woman would be more hesitant to disclose this information in the future. Some participants may delay sharing certain information until the provider relationship is more established.

Researchers increasingly study how patients strategically manage potentially stigmatizing information such as sexual abuse, HIV status, sexual orientation, or high-risk behaviors. This research also includes how people share this information with family, friends, and partners, as well as with health care providers. The challenge with delay and nonsharing is how the information could affect the diagnosis or treatment plan. Patients weigh the possible relevance of information that they may not view as directly connected to the current health issue (e.g., family history) with the potential negative outcomes. For example, there is widespread patient nondisclosure of their complementary and alternative medicine use; in this case, the provider generally does not inquire, but the patient could view the information as irrelevant, or the patient may not share in order to avoid the provider's disapproval.

It is known that patients assess providers' responses to sharing certain information and may choose to share incrementally or gradually. This incremental sharing (or testing reactions) may be especially difficult in the unique context in which treatment decisions may be made in a mere 10 or 15 minutes. If patients receive encouraging responses, they may share more, but if they perceive they are being judged or ignored they may limit further sharing. For example, lesbian, gay, bisexual, transgendered, and/or queer (LGBTQ) patients report using the term *partner* with providers to probe or test potential responses. Specifically, if a man makes a passing reference to his partner, does the physician assume that the partner is a "she," or that the patient means a business partner? For a gay man, this could be a potentially problematic interaction that might serve as an indication that sharing his sexual orientation directly or disclosing his past sexual history could be awkward or problematic. These situations can lead to active disclosure avoidance beyond not sharing.

Consider the following complicated screening interaction for a lesbian prior to a mammogram after reporting her last menstrual cycle:

Nurse: Is there any chance that you are or could be pregnant?

Patient: No.

Nurse: Oh, so you aren't sexually active?

Patient: Yes, I am. But I cannot be pregnant.

Nurse: I see. Did you have surgery? Did your boyfriend have a vasectomy?

Patient: Can we just agree that it's not possible for me to be pregnant?

The provider is trying to follow protocols to ensure that the patient is not pregnant (the procedure could harm a fetus). Unfortunately, the interaction was likely not satisfying for either the nurse or the patient. The patient does not feel that she should be required to disclose her sexuality to the provider, while the provider is trying to complete a task and failing to pick up indirect cues.

Encouraging or Discouraging Disclosure

Certain kinds of physician behaviors have been shown to encourage or discourage patient elaboration and disclosure. Some research has investigated what strategies providers can use to elicit more complete patient disclosure. One key phenomenon in this process is question-asking. Specifically, open versus close-ended questions can promote or inhibit patient disclosure. Open questions include queries that leave the possible response unstructured, such as a general inquiry, "Why are you here today?" Closed questions imply a preference for a specific format of response such as "When was the last time you had a tetanus shot?" Some closed questions are designed to solicit a yes or no response, such as "Do you smoke?" Open questions produce more information sharing, but some providers are concerned that open questions may solicit too much unrelated information (and increase visit length, a difficult issue with managed care restrictions). Open-directive questions promote and leading questions inhibit disclosure.

Other behaviors that promote disclosure include focus on psychosocial issues, empathic statements, and summarizing behaviors, while focus on physical aspects and moving to advice or reassurance inhibits patient sharing. Eliciting disclosure (and types of question-asking) is currently included as a component in most physician training programs in which physicians may practice

history taking with standardized patients. Physicians can be trained to increase information obtained through the use of certain types of direct and indirect questions, but it is not known how long these training effects last or if gains are sustained. Unfortunately, physicians also struggle with eliciting (and responding to) psychosocial information, and psychosocial issues may be a crucial component in disease management or sustained behavior change. Little is known about how to facilitate patient sharing of emotional concerns beyond relevant medical history.

In a medical interaction, providers often initiate and patients respond, and this establishes an interaction pattern that may make disclosure of sensitive topics difficult. This phenomenon is confounded in a culture dominated by norms against individuals sharing private information with people they do not know well. The consultation is an interpersonal process that is dominated by dialectical concerns in which people balance what (and how) they share to maximize benefits and minimize costs. In this context, the disclosure benefits include efficient use of time, accurate diagnosis, and better understanding of the medical condition, yet the costs of that sharing could be embarrassment, feeling judged or stigmatized, or exposing ignorance. The face-to-face nature of much of the consultation, compared to the medical questionnaire, may intensify patient concerns regarding disclosure of sensitive information. The interaction is particularly face threatening for the patient, with the physician seen as a high status and knowledgeable expert, perhaps older, with potential cultural nonconcordance. Concern about face threats will decrease disclosure for patients, and this has led to focus on how to establish rapport.

Providers can be trained to establish rapport in a way that creates a climate for sharing. Some patients must be “put at ease,” for example, when visiting the dentist, gynecologist, or a therapist. Some providers may initiate the interaction with small talk (“I see you’re a Cubs fan!”) or use humor to set the context for patient comfort and disclosure. In contrast, some providers (specialists in particular) have reputations for having “no bedside manner.” Some research on rapport focuses on nonverbal cues. Nonverbal cues studied include eye contact (gaze), body orientation,

proximity and touch, and similarity; verbal and nonverbal cues are intertwined.

Some methods that providers can use to elicit disclosure are subtle and may require the provider to draw inferences. There are certain conditions in the provider–patient interaction in which providers must probe for more information, such as when a provider observes patient changes or a general lack of comfort throughout a visit. For example, if a physician asks a woman “Are you or have you ever been in a physically or emotionally abusive relationship?” and the patient pauses before answering “No,” this could be an indicator of the need for follow-up to elicit full disclosure. As another example, when a patient cannot fill out a medical form due to literacy issues, patients may report “I forgot my glasses” rather than share that they cannot read. If a provider misses these cues, then providing written material, providing a Web site for information, or even expecting patients to read directions on a medication bottle could lead to very poor outcomes.

Bad News Disclosure

One particularly troubling topic of disclosure for both physicians and patients is end-of-life discussions and/or disease prognosis, as both providers and patients may avoid this topic. The dominant U.S. culture is death-avoidant, and some cultures may also be high in avoidance of terminal prognosis discussions. Despite this avoidance, there is increasing emphasis on palliative care and family decision making in this context in which focus shifts from treatment to providing comfort. During the palliative phase, the interactions often become triadic (or family-oriented) rather than the predominant dyadic context in which most disclosure research occurs. Care providers report challenges when initiating end-of-life or prognosis discussions, and they consistently underestimate patients’ desire to have them. This is in contrast to patients reporting desire for full (and timely) sharing of medical information. Patients may express relevant desires in a variety of advance directives (also a form of patient disclosure), but, unfortunately, physicians often do not read these documents (nurses are more likely to read them).

Physicians receive specific training in “breaking the bad news,” something that they label disclosure of a diagnosis. This is not personal

information that a physician is sharing; rather, it is the patient's medical news. There is a clear difference between telling a patient "your strep test was positive" and "you have multiple sclerosis." A diagnosis of multiple sclerosis is generally not considered life-threatening but certainly is life-altering for a patient, similar to many chronic conditions. Providers describe this process as particularly stressful and are often depressed after sharing. Telling a patient the diagnosis is difficult and unpleasant, and providers, especially specialists, find ways to "routinize" this task. This "news" sharing is further complicated in cultures in which full disclosure to patients (and/or families) is unclear, or relatives specifically request that the provider withhold the diagnosis from the patient.

One part of this challenge involves health care providers' assessments of what they think patients want to know, when, and in what level of detail. Some research has focused on prognosis information or what patients might want to know regarding the disease progression of "How many months do I have left, Doc?" There is more research on how to share a diagnosis than when to share a serious and/or incurable diagnosis, and providers struggle to decide if they should share all relevant information with patients. Would it be more beneficial to gradually share information with the patient while allowing for phases of adjustment? There is no research to date to guide this decision, such as to sequence the information, other than patients who report wanting to know the full information when it is available.

Disclosure in the Presence of Others

An additional complication for patient disclosure is the presence of other parties. Patients increasingly attend medical appointments accompanied by another person who may be a partner/spouse, friend, or family member. Some groups advocate that another person accompany the patient to medical appointments. Some benefits of proxies or health care advocates attending visits can be to: ask clarifying questions, provide information, recall information, provide emotional support (e.g., in visits where a diagnosis is shared), or assist with social support for behavior change. Bringing a companion or health care advocate (or multiple people) to the visit can change the

disclosure dynamics in several ways that may detract from the benefits. Some providers may communicate directly with the proxy rather than with the patient. In some cases this redirection may be appropriate (e.g., if the patient is a child or if the patient has diminished capacity such as with Alzheimer's disease), but in others this behavior could discourage patient disclosure if the patient feels less involved. The accompanying person sometimes actually enacts the disclosing rather than the patient (a specialized form of third-party disclosure), including reporting symptoms, answering provider questions verbally, and/or even filling out the intake questionnaire. There is to date no research on how accurate this disclosure is or under what conditions the patient might elaborate or address incorrect or misleading information shared by the advocate.

There is limited research on families or couples who attend visits, but what little evidence exists implies that the presence of proxies may suppress certain kinds of patient disclosure. For example, spouses often report "we share everything" related to a health condition, however, these same patients also report that they would never discuss sexual side effects or fear of death with their spouse/partner. Thus, more research is needed on when and why the presence of others further contributes to disclosure dilemmas in the patient-provider context.

For some sensitive topics (e.g., sexual side effects, risk behaviors, or end of life) providers may be more effective speaking to patients without a spouse (or family member) present. Imagine asking patients (with spouse or child present) how many sexual partners they had in the past year? Conversely, it is difficult for a patient to discuss sexual function (or request a Viagra prescription) comfortably if a spouse/partner or another family member is present.

Conclusion

The patient-provider interaction holds an important role in the provision of health care. Focus on disclosure has potential to significantly improve interactions for both providers and patients. These positive outcomes could include maximizing use of time and resources while simultaneously increasing care, adherence, and satisfaction. This is an area of research in which a great

deal has been learned, yet many questions remain unanswered. As provider interactions continue to change, the emphasis on disclosure will remain a key feature.

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See Also: Bad News, Communicating; Communication Skills Training and Assessment: Providers; Communication Skills Training: Patients; Death and Dying; HIV/AIDS Disclosure Dilemmas; Information Sharing; Palliative Care.

Further Readings

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Discourse and Health

The relationship between discourse and health has been approached from two contending traditions. The first is largely rooted in French scholarship, especially the meditations of Michel Foucault. Focusing predominantly on the emergence of modern clinical practice and medical institutions (e.g., hospitals, asylums), it views discourse as the expression of an institutional strategy of normalization and control. The second, which is largely made up of Anglo scholars, perceives discourse as the expression of multiple voices that are manifest at micro (i.e., interpersonal and individual), meso (i.e., organizational), and macro (i.e., social) levels within the context of health communication. Both perspectives have contributed to a better understanding of the role of discourse in influencing societal perceptions and expectations about

health issues, while drawing attention to the link between power and language within the context of medicine and health care.

Foucault's contribution to the field is premised on the notion that discourse serves to normalize views and practices associated with health and hygiene through a knowledge that defines the parameters of "normality" and "abnormality." In this regard, he understands discourse as both the expression of certain ideas, and a pragmatic endeavor aimed at subjugating the body by institutionally framing it within the structure of the hospital or the asylum. To this end, Foucault situates discourse in a larger context he calls "biopower"—the technology of power aimed at controlling large populations as bodies to be disciplined—which he views as being vital to the emergence and functioning of the modern nation state.

Discourse can also be approached, however, as part of the communicative production associated with health and medicine. Here, discourse is understood as the expression through language of the intentions, expectations, and perceptions of different actors. Deborah Lupton, for instance, defines discourse as a polyphonic web of texts, messages, talks, dialogue, or conversation from and among different players in the context of health care and medicine. Viewed in this manner, discourse is the matter to be analyzed to uncover and/or discover communicative expressions and prescriptions that circulate in a society. This implies a methodological orientation that privileges discourse analysis as a crucial mechanism for providing comprehensive accounts of the social, political, and cultural dynamics shaping the public understanding of medicine and health. The objective is to transcend the mere decoding of manifest content (for example, the frequency of certain words) by analyzing the explicit and implicit meaning conveyed through a variety of textual and verbal manifestations.

Susan Sontag's 1977 essay on illness as a metaphor is a seminal work in the field of discourse and health. Her study—a blend of the two aforementioned traditions—set the tone for subsequent analyses by illuminating the link between the public understanding of cancer and tuberculosis and the sociocultural and sociopolitical climates of the 19th and 20th centuries. Sontag's juxtaposition of the romanticized tropes defining