

# Training Patient and Family Storytellers and Patient and Family Faculty

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## Abstract

Narrative medicine has become a prominent method of developing more empathetic relationships between medical clinicians and patients, on the basis of a deeper understanding of the patient experience. Beyond its usefulness during clinical encounters, patient storytelling can inform processes and procedures in Advisory Councils, Committee Meetings, and Family as Faculty settings, leading to improved quality and safety in health care. Armed with a better understanding of the patient experience, clinicians and administrators can make decisions, hopefully in collaboration with patients, that will enrich the patient experience and increase satisfaction among patients, families, and staff. Patient and family storytelling is a key component of the collaboration that is ideal when an organization seeks to deliver patient- and family-centered care.

Providing patients and families with training will make the narratives they share more powerful. Health care organizations will find that purposeful storytelling can be an invaluable aspect of a patient- and family-centered culture. Well-delivered storytelling will support quality- and safety-improvement efforts and contribute to improved patient satisfaction. This article provides instruction for teaching patients and families how to tell stories with purpose and offers advice about how to support patients, families, and clinicians participating in this effort.

## Introduction

Narrative medicine has become a prominent method of developing more empathetic relationships between medical clinicians and patients, on the basis of a deeper understanding of the patient experience. Beyond its usefulness during clinical encounters, patient storytelling can inform processes and procedures in Advisory Council, Committee Meetings, and Family as Faculty settings, leading to improved quality and safety in health care. Armed with a better understanding of the patient experience, clinicians and administrators can make decisions, hopefully in collaboration with patients, that will enrich the patient experience and increase satisfaction among patients, families, and staff. Patient and family storytelling is a key component to the collaboration that is ideal when an organization seeks to deliver patient- and family-centered care.

Although a wealth of literature discusses narrative medicine from the clinician's perspective, very little has been written about how to help patients tell their own story in an effective and powerful way.<sup>1,2</sup> Without guidance, patient storytelling runs

the risk of being unfocused or poorly received. With guidance, patient and family storytellers can deliver powerful messages to their intended audience. This article gives instruction on teaching patients and families to effectively tell their story and offers counsel about how to support patients, families, and clinicians participating in this effort.

## A Personal Story

I (LM) entered the realm of storytelling many years ago as a patient advocate and member of Primary Children's Medical Center's Family Advisory Council. My preteen daughter was asked to join me in sharing insights into the patient experience with the nursing residency program. Because of medical dependency despite her young age, she had attended many of the college classes I taught in business communications and public speaking. Together we learned how to present our message to the nurses. The message my daughter and I shared included encouragement to the nursing staff, along with observations about quality and safety issues. My daughter and I learned which aspects of our story would have the greatest impact on the nurses' practice.

Most patient or family storytellers need training because they lack extensive experience in sharing their personal narrative and/or in public speaking. That lack of experience can work against the untrained storyteller.

When my (LM's) advocacy role extended to training and working with numerous other patient advocates as the Patient Experience Coordinator at Primary Children's Medical Center, we (LM and KJS) designed a program that proved effective in assisting families to share stories in a number of hospital venues.

## Storytelling Guideline Development

Guidelines for selecting patients or family members vary, but we generally suggest that the individual have at least one year of advocacy experience before formal storytelling. In that year, the storytellers learn they are not alone in the hospital experience, and their understanding of the importance of representing all patients and families gives them a broader perspective. The first thing we assess is whether or not the storytellers are emotionally ready to share their stories. Patients or family members need not be dispassionate, but they should not vent or have an accusatory tone when telling about their experience, especially if they had a negative encounter. Otherwise, the audience will not likely be able to hear their message.

We ask new potential family storytellers to observe more experienced family advisors. This gives newer storytellers the

opportunity not only to see others deliver a message, but also to learn about the level of audience engagement and the kind of questions they will likely be asked after sharing their story.

Patient or family storytellers must know the goal of their presentation and to whom they will be talking. Our patient advisors participate in training nurses, medical students, residents, and attending physicians. The message is tailored to each situation. For example, when speaking to nurses, one family shares a story about a nurse who knew the patient liked the Power Rangers and always karate-kicked her way into the room, delighting the child. When our families train medical students, they tell about physicians who took the time to listen and to answer their questions. We help patients and families tailor their presentation by discussing ahead of time who will be in the audience.

### Storytelling Goals

The organization can help the storyteller frame the narrative by defining the goal. Three typical goals are

1. to evoke strong emotion (typically in lobbying or fundraising contexts);
2. to promote empathy and understanding (helpful in supporting culture shift and communication skills); and
3. to promote change (helpful in influencing process or policy).

Evoking strong emotion helps in lobbying for medical or community efforts. I (LM) was once asked to lobby for additional Medicaid funding for technology-dependent children. Several parents and their children had packed the room. Every so often, a loud noise like some sort of heating or air conditioning unit cycling on and off would fill the room. The Medicaid Advisory Panel, including the Chief Executive Officer of the children's hospital and several legislators and representatives from the Department of Health, were noticeably annoyed with the noise and wondered out loud why the heating, ventilation, and air conditioning system was so loud. When I got up to speak, I explained to those gathered that every time the noise occurred, a mother in the room was suctioning her child's tracheotomy. The sound the audience was hearing was portable suctioning equipment. That suctioning was necessary 24 hours a day, 7 days a week, which was why we were requesting funds for more home nursing care for these children. The Advisory Panel was visibly moved and voted later to increase the funding.

To promote empathy and understanding, we ask our storytellers to share briefly how their encounters with our hospital make them feel. The family members receive training in using "I" statements and first person language. They use statements like, "I feel like I am not being heard when you ask me the same questions over and over again," or "I feel like you don't care who I am as a person when you call me 'mom' or 'dad' instead of by my name." Hearing family members state their feelings has helped staff focus on their listening skills and to ask family members how they would like to be addressed. When the speaker uses "I" statements, audience members are less likely to feel they are being singled out or personally attacked.

Influencing process and policy also involves being able to pull out brief vignettes that are specific to the issue being discussed. Youth advisors were recently invited to comment on food services. They noted that the domes that came with the food trays

seemed to be contributing to nausea and loss of appetite. Food service policy was changed, and the domes are now removed before the trays are taken into patient rooms. The youth advisors did not need to tell their entire story, from diagnosis, to chemotherapy treatment, to their current status, to make their point. Instead, a simple explanation that the aroma of the domes made them want to "barf" was all that was needed.

### Storytelling Process

For most families, a huge, culturally based power gap exists between the family and the clinicians with whom they interact. Educational and socioeconomic differences can be barriers to the family's feeling comfortable sharing their story or to the audience's ability to receive the message. At one family panel presentation, an audience member made a disparaging remark about greeters at a big-box store. The mother of one of the family panelists had a job as a greeter. We learned to prepare the family members to remain open to sharing with the staff despite their differences.

As staff spends more time hearing from and interacting with family advisors, they too learn to be more accepting of different cultural backgrounds. Sometimes the cultural differences between the storyteller and the audience can interfere with the staff's hearing the intended message. Teaching staff to suspend judgment and to find common ground is very helpful. We find that family advisors from significantly different backgrounds can connect on the basis of the commonality of their health care experience. Similarly, staff and family members may connect on the basis of shared experiences with hobbies or other matters.

Patients and family members are often asked to condense the diagnosis and treatment portion of their story into one very brief statement that can be used as an introduction. Some have lengthy medical files. At first, they may find that offering a succinct explanation of their reason for speaking is difficult. With time, they learn that the diagnosis and complicated history are secondary to the point they want to make.

### The 75-Word Challenge

I (LM) suggested the 75-word challenge to one group of patient advocates: the storyteller was to attempt to summarize their diagnosis, treatment, and current condition in no more than 75 words. My personal 75-word statement is:

*My daughter was born unable to breathe or swallow because of a birth defect. She has benefited from advances in medicine and informed, caring, skilled clinicians. She has also suffered from complications because of failure to appropriately resuscitate, inappropriate surgical intervention, inappropriate diagnoses—including meningitis—and other mistakes. I became a patient advocate partially for my own daughter, and to help other parents. I advocate for change in the largest Utah-based health care system.*

Once the patient and family member know to whom they are speaking and why, they can craft two or three main ideas to illustrate their point. To assist our storytellers, we provide guidelines to include a brief summary of their story, an experience that was challenging or successful, and the way they use support staff to solve problems. In addition, we talk to the patient

or family member in person and help them outline their main ideas. Then, we encourage them to use their notes during their presentation. Some prefer to use a sheet of paper, and others choose to carry a note card.

Some storytellers become accustomed to telling their stories and leave their note cards behind. Although some manage to speak extemporaneously, others find they get off track and lose their focus. We have learned to provide each storyteller with an outline each time.

The story's conclusion should relate to the goal of the story. Many of the family storytellers we ask to participate in Family Faculty settings choose to close by thanking the clinicians for their willingness to listen. Others may share a plea for more empathetic listening or better efforts to coordinate care. One storyteller has a child with cerebral palsy secondary to meningitis. The initial source of the meningitis appears to have been respiratory syncytial virus transmitted by a nurse who had failed to wash her hands. After she calmly told her story about the nurse with a cold in the neonatal intensive care unit and asked for more vigilance in hand washing, the staff provided feedback and plans to be more diligent in washing their hands.

### A Receptive Audience

Narrative medicine will not be effective if the audience is not receptive. We found that when patients and families only told aspects of their encounters that were critical of staff, the latter did not hear the message. We learned to help our storytellers frame their ideas in a positive way. Instead of saying, "I don't like it when you ask me the same question over and over again," the Family Faculty member may say, "I appreciate those clinicians who take the time to review our records before they come in the room and ask me if I have something to add." Or, our Family Faculty will start their narrative with a vignette about a nurse who did them a special favor, then discuss how nurses should be careful about what they say outside patient rooms because the patients may be able to hear them.

To illustrate that point, my (LM's) daughter tells nurses of their colleague who searched high and low for a certain pudding for my daughter to use when taking some medicine. What a thoughtful nurse! Then she tells about the time she came back from a procedure during which she had been sedated; I told her she did great, but the nurse in the hall told the other nurses how much my daughter had fought everyone. My daughter heard every word the nurse in the hall said. My daughter explains she was embarrassed and felt like she couldn't trust her mother after hearing the nurse describe her wild behavior while under the influence of midazolam.

As family storytellers become more comfortable telling their stories, we help them work on some of the basic mechanics of delivery. One parent Family Faculty member was having a difficult time, for example, with eye contact with the audience. She felt shy, because members of the audience had so much more education and earning power than she had. We worked on visualizing the audience as the small children she taught in her church. I (LM) would also stand at the back of the room so she could scan the audience and then look at me. Other storytellers may need support with issues like rate, pitch, and pausing.

Training of family storytellers is both formal and ongoing. Individual coaching occurs after presentations. All families participating in our Family as Faculty and on our Advisory Councils receive basic storytelling training. This is a simple, 30-minute explanation of the importance of using the part of their story that informs the question being addressed, remembering to use "I" statements, including positive thoughts as well as problems, and how emotion may affect their effort. For formal storytelling events (nursing residency, medical student training, grand rounds), family members receive an outline to complete in advance.

We generally choose not to use electronic presentation programs; however, we do often project photos of the patient and family members in their home environment. This helps build rapport, as the audience can see the patient and family as "real" people, engaged in the community and normal daily activity.

### An Emotional Challenge

Storytellers may discover that their emotions enter the storytelling in ways they had not anticipated. One parent does an incredibly effective job of telling her story, and she always cries. Her crying is a part of telling a very difficult story and is not off-putting—she can talk through her tears and remains somewhat composed. Her story never fails to move the audience, in part because she is so genuine.

Some parents are surprised at the level of emotion they feel when telling their stories. Even if they practice and are calm, cool, and collected before they get in front of their audience, their emotions may choose to join in the storytelling. One mother recently addressed a group of chaplains, explaining what spiritual supports would have been helpful when one of her children was dying from an infection secondary to chemotherapy and another was in the same hospital, on a different floor, also receiving chemotherapy. She did not anticipate, since she had practiced her presentation and dealt with her emotions, that she would be in tears as she shared her feelings. Coaching storytellers about the emotions they may experience may help them cope with their feelings. They will also feel reassured if told ahead of time that surfacing emotions are normal. We also make sure that we have tissues close at hand.

After patients or family members share their story, we visit with them briefly, at which time we assess whether the storyteller feels comfortable with their storytelling experience and their feelings. We do not offer counseling to our family advisors but refer them to the appropriate professionals if necessary.

Equally important is gauging the emotional status of the audience after storytelling. One resident physician listened to a teen patient dispassionately share his story of feeling largely ignored by clinicians during hospitalization for transplantation at age four. The teen patient explained that he was unable to talk but knew what people were saying. He expressed his extreme frustration that no clinicians explained to him, in terms he could understand, what was happening to him. The teen's story had a strong impact on the resident physician. The resident indicated that this one story may have informed her practice more than any other aspect of her training. She then related a personal experience and feelings that were triggered by the young man's story, accompanied by strong emotions and tearfulness. Other

staff listened to her concerns and suggested the resident look into some available options for talking out her feelings.

One way to help the audience understand their response and connect to the message is narrative processing after the storyteller is no longer present. Narrative processing goes beyond simple discussion. Its purpose is to stabilize the group and identify any therapeutic needs that should be followed-up differently. This may include an emotional response that seems out of proportion with the information that was presented.

### Audience Guidelines

The following guidelines will help your audience process their feelings about what they have heard:

1. Review, in general, what the experience was like. Listen without offering judgment.
2. Explore their response. Ask follow-up questions, if necessary. If an audience member brings up a previous traumatic event, be prepared to follow up later with a referral for more in-depth, therapeutic listening.
3. Explore the helpfulness of the message in terms of information and presentation. If the audience members feel the message was critical of their performance, explore how the presentation may be improved to create an environment of partnership.
4. Once the audience has had an opportunity to express their feelings, ask about the take-away message, in terms of policy or process change. Explore institutional and leadership supports that can bring about positive change. Help the audience come back to the point of the discussion and lead the dialogue toward collaborative problem solving.

In our Family Faculty efforts, we thought we had carefully helped our storytellers craft effective messages. We have observed that even fairly simple expressions of feelings of patients and family members can evoke tremendous defensiveness on the part of all classes of clinical staff. We have had to go beyond

simple positive reframing. We now work on relationship building, helping our storytellers make statements that reflect empathy for caregivers. We also find that coupling clinician storytellers with patient storytellers can send a more powerful message. Clinician storytellers can often share or model communication skill sets that address the issues raised by the patients. The clinicians can also model responses to patient stories that are particularly helpful for newer clinicians.

### Conclusion

We measure success by feedback received during evaluations and discussions that follow storytelling. Comments such as, "This was the most valuable presentation we received during Nurse in Residency," and "I wish we had more parent and patient panels!" are the norm. Most respondents give the family presentations top scores.

Providing patients and families with training will make the narratives they share more powerful. Health care organizations will find that purposeful storytelling can be an invaluable aspect of a patient- and family-centered culture. Well-delivered storytelling will support quality- and safety-improvement efforts and contribute to improved patient satisfaction. ❖

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