Collecting Patient Experience Stories

Description

Even if people receive care that is technically excellent, the experiences they have as patients color their memories of that care. Organizations routinely measure patient satisfaction but rarely seek to learn about patients’ actual experiences of care. The stories patients tell are a fantastic source of information about how well we deliver care and where to focus improvement.

Despite months of efforts to reduce orthopedic surgery waiting times, and despite what staff thought was an apparently trouble-free admission and surgery, a patient on an orthopedic ward in the UK said, “You cared for me, but you didn’t care about me. It was totally impersonal, yet for me, [surgery] was a major life event.”

Do we really know what our patients see and feel? They and their families observe every step of the process, and their experiences can be affected by many things: the attitudes of both clinical and non-clinical staff, noise, smells, tastes, lighting, signage, parking, and cleanliness—along with more obvious issues such as waiting times, pain management, and so on.

Collecting Patient Experience Stories

Begin by identifying someone you know who has had an experience with health care—either as a patient or as a family member of a patient. You might choose a relative, friend, colleague or neighbor. We suggest that you do not use patients who are currently receiving care within your organization. You can do this activity either one-on-one or facilitate it with a group.

Before you Collect the Story

- Explain why you are doing this. You might say:
  “I am a nursing/medical/pharmacy/management student and we want to know more about what patients and their families experience in health care, so that we can one day improve services for you.”

- Ask if you can record the story using video, audio or note-taking to:
  - enable you to listen to it again;
  - analyze it to highlight themes for improvement;
  - share it with others via the Institute for Healthcare Improvement (IHI) Open School website, where a Patient Experience Story Bank will be established for teaching and development purposes.
• Ask the person to sign two copies of the IHI consent form before the interview – one for you and one for IHI.

• Be ethical:
  ➢ Respect the person’s desire for privacy and/or anonymity.
  ➢ Ensure the person understands you wish to use his story in your work, and make sure that you have his permission to do so.
  ➢ Ensure the person understands his story may appear on the IHI website, if he consents to this. If the patient is willing to sign the IHI consent form, he should do so before telling you his story.
  ➢ Make sure the patient understands that his care won’t be affected directly by what he tells you.

• Ask the person how he would like to identify himself. He can use a first or full name, he can choose to give no identification at all, or he can use a pseudonym.

• Ask the person not to name the organization where he had treatment.

• Find a quiet place where you won’t be disturbed and the person can relax.

• Depending on what the patient agrees to, have a video camera, audio recorder, and/or pen and paper ready. If you are using any kind of recording device, be sure to bring a power source or extra batteries.

• Technical Requirements: video must be saved in .wmv or .mov format, and audio must be saved in .mp3 format.

Hearing the Story

• Invite the patient to tell you his experience of health care. He can either tell the story from the very beginning or pick one aspect (such as a recent flare-up of his condition or a recent admission to the hospital). Accept that he might say no to your invitation!

• Ask the person to think about a specific time when he had problems with his health and saw a health care provider about it; or a time when he was in a care giving role for a family member or friend.
  ➢ Invite him to describe in the experience in specific detail. What were his fears, frustrations, inconveniences, and uncertainties?
  ➢ What does he wish had happened that did not happen?
  ➢ What was the hardest part about being a patient in the health care system?
  ➢ What positive and/or surprising experiences did he have?
• Make no judgments, and don’t explain or teach! Do not defend yourself or the health care system. This is the other person’s experience, not yours. Just listen.

• Use open-ended questions (what, how, why, when, where). Try not to talk too much. This isn’t an interview. Take brief notes if necessary and write them up immediately after the patient or family member finishes talking to you.

• Detailed, end-to-end patient experience stories can take an hour or more and generate a lot of material to analyze. But even an interview of just four or five minutes can provide very useful feedback.

**After the Story**

• Thank the person.

• Reiterate how you will use the story within your Chapter, in your coursework, etc.

• Repeat that you will share the story through the IHI Open School network and on the IHI website, if the person has consented to this.

• Make sure you have two signed copies of the consent form.

• Send the story and one of the signed consent forms to openschool@ihi.org. (If the file is too large to send via your email provider, you can use a free online service like YouSendIt.)