The Importance of Narrative: Open Notes, Patient Stories, Human Connection

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Speaker Introduction

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Conflict of Interest

Dr. Kathy Nieder and Jan Oldenburg

Have no real or apparent conflicts of interest to report.
Agenda

• Importance of narrative and stories in clinical care
• Developing a listening culture
• Showcasing listening in your organization:
  – In patient councils
  – In how you respond when things go wrong
  – In social listening
• Conclusions
Learning Objectives

• Learning Objective 1: Discuss how to assess how patient stories are valued within your organization’s practice of medicine

• Learning Objective 2: Describe how to incorporate narrative into policy and practice as a way of developing stronger healing relationships between patients and physicians

• Learning Objective 3: Assess how Open Notes can be used to empower patients in relation to their own health and wellbeing.
An Introduction of How Benefits Were Realized for the Value of Health IT
Listening matters

• *Illnesses unfold as stories*, and physicians need to learn how to listen to those stories.²

• Furthermore, *listening carefully* to individual stories acknowledges personal engagement and fosters motivation…¹

• By the very act of listening, we ourselves are always changed into different kinds of listeners²

Listening matters

- Rita Charon, one of the founders of the narrative medicine movement, says that scientific competence alone “cannot help a patient grapple with the loss of health or find meaning in suffering. Along with scientific ability, physicians need the ability to *listen to the narratives of the patient, grasp and honour their meanings, and be moved to act on the patient’s behalf*” ¹

1. [http://jamanetwork.com/journals/jama/fullarticle/194300](http://jamanetwork.com/journals/jama/fullarticle/194300)
Current medicine often leaves patients feeling like this...

"The doctor will see you now – I can’t promise that he’ll talk to you, but he’ll see you."

Source: www.jantoo.com
Components of a healing relationship

Impact for patient: Trust, hope, and the sense of being known

Impact for provider: Reduced burnout and increased sense of hope

1. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2478496
Listening to stories is healing

For patients:

• People with high blood pressure who listened to peers tell stories of coping with high blood pressure were more successful at lowering their blood pressure than those who listened to unrelated stories

1

• People who keep journals have more immune cells, decreased symptoms of asthma and rheumatoid arthritis

2

For physicians:

• “Physicians continue to control the most sacred and meaningful aspect of medical practice—the encounter with the patient and the reward that comes from restoring health and relieving suffering. Reminding physicians of this fact and helping them recognize and enhance the meaning they derive from the practice of medicine may help protect against burnout and promote patient-centered care for the benefit of both.”

Bringing patients into the center

Geisinger: Listening AND putting their money at risk with ProvenExperience

Patients and Design thinking are at the center of everything at Radboud University Hospital in the Netherlands

“As a doctor you are really a co-author of patients’ experiences and need to hear their story and take it on,” Dr. Abigail Ford

What technologies support including patient stories? Patient Portals
What technologies support including patient stories? Open Notes

• More than 11M people already have access to clinician’s notes
• The goal is 50M over the next three years
• Preliminary outcomes:
  – More transparency between patients and clinicians
  – Improved patient safety
  – 77-85% of participants reported better understanding of their health and medical conditions
  – 77-87% felt more in control of their care
  – 70-72% said they took better care of themselves
  – 60-78% reported doing better with taking their medications.

Source: 1) http://www.opennotes.org/
2) http://www.rwjf.org/content/dam/farm/farm/books/books/2014/rwjf411535
What technologies support including patient stories? Self Tracking
But narratives tend to be missing from EHRs

- Clinical summaries are often lists of facts absent physician or patient narratives
- What’s lost in healing and care when we lose the narrative?
Example: EHR record with facts but no narrative

Patient is a 77 y.o. female presenting with skin laceration
History provided by: Patient
Laceration
Location: Shoulder/arm
Shoulder/arm laceration location: R elbow
Length: 3cm
Depth: Cutaneous
Quality: Avulsion
Bleeding: Controlled

Time since incident: 60 minutes
Laceration mechanism: Fall
Foreign boy present: No foreign bodies
Relieved by: Nothing
Worsened by: Nothing
Ineffective treatments: None tried
Example: Contrasting narrative version:

She was sitting down reading a book, she got up to answer the phone (about three feet away), picked it up and after a minute or two she passed out. She doesn’t remember feeling faint or dizzy. She had no symptoms. She doesn't think she was out that long and when she got up she drove herself to the ICC afterwards without a problem. The ICC had her return to monitor her skin tear for three more visits. She has had multiple dizzy episodes over the last couple of months. She doesn't check her BP at home though she has a cuff. She has not seen the cardiologist in some time. She is not on any new medications.
Really valuing patient stories is more than this

“Of course I’m listening to your expression of spiritual suffering. Don’t you see me making eye contact, striking an open posture, leaning towards you and nodding empathetically?”

Source: www.cartoonstock.com
Listening to patients is more than monitoring your Press Ganey scores

She’s calling for a health care revolution. The radical first step: listen to patients

Complaints - is anyone listening?

Patient centricity: authentic engagement or lip service?

Empathic Approach: Listening First Aid

Lip Service To Patients And Caregivers, Or Respect?

Listening Matters, Whatever the Situation
Organizations telegraph whether and how much listening to patients matters:

• What matters in the medical record
• The nature of patient councils
• How medical errors are handled
• Their social media stance regarding broadcasting vs listening
Family Councils reflect organizational values

<table>
<thead>
<tr>
<th>Levels of engagement</th>
<th>Continuum of Patient/Family Engagement</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Consultation</td>
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<tr>
<td>Direct care</td>
<td>Patients receive information and instructions about a condition or diagnosis</td>
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<tr>
<td>Organizational design and governance</td>
<td>Organization surveys patients about their care experiences and goals</td>
</tr>
<tr>
<td>Policy-making</td>
<td>Organization conducts focus groups with patients to ask opinions about healthcare issues</td>
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</tbody>
</table>

Source: Adapted from Sample Consumer Engagement Framework American Institutes for Research
http://forces4quality.org/print-preview/6771.html
Developing a listening culture:

• It can start either top down and bottom up
• Eventually needs an organizational champion
• Highlight value by bringing patients to the center:
  – Bring them in as strategic partners
  – Get serious about making them the center of process and system design
  – Model behaviors by showing that leaders have things to learn from patients as well
Consider your patient and family councils

- Do you have one—or more?
- Does it have the ear of the Board?
- What kinds of issues does the patient and family council address?
  - New pajamas?
  - Patient care problems?
  - Organizational policies?
  - Funding decisions?
- Patients and families understand the difference between being a part of meaningful decisions vs “showcase” decisions
When things go wrong...

- Who handles the complaint?
- Do your lawyers shut down discussions with the person or family?
- Do you use the situation as a “teachable moment” to improve?
- Do you post error rates publicly and what you’re doing to improve?
- 40% of people who file malpractice claims say they wouldn’t have if they had received an explanation and apology

Communication and resolution approaches pioneered at the University of Michigan, have been shown to reduce malpractice lawsuits

Susan’s story

• Consulting professional in Minneapolis, MN
• Hospitalized with Guillain–Barré syndrome, everything paralyzed except respiration
• Her physician punctured her lung inserting a chest tube—and wouldn’t acknowledge it

Her doctor’s refusal to acknowledge or apologize for the error eroded Susan’s sense of safety and support

Source: Participatory Healthcare, ed Jan Oldenburg. “Story 13: I suggest you check yourself into the hospital.”
Health plans understand social care...

**UHG Service Cntr Jobs** @UHGSvcCntr · 6 Jul 2016

#Healthcare can be complex & at times very cold. See how our #customercare teams help to diminish that. uhg.hr/1QoA7k9 @Optum

**Kaiser Permanente** @KPMemberService · 28 Dec 2016

@JDcarlu Hi, I noticed your tweet, is assistance needed? If so, please email me direct Attn: Jon to KP-Member-Services@kp.org

**Humana Help** @HumanaHelp · Jan 6

Hello @naw8. We’re sorry to hear this. Please DM us your name, email, phone, ZIP and summary of your issue so we may assist. Thank you. - HG
Social media—are you broadcasting or having a conversation?

• Make sure you are listening as well as talking
• Mine your data for positive and negative “sentiments” associated with your organization—and have a response plan
• Consider your social care strategy:
  – When people complain about service via social media, respond—even if you have to send them to an off-line channel
  – After you’ve resolved it, post it via social media
  – Better yet, ask the complainer to post the resolution via social media
  – You have an opportunity to turn negative perceptions into positive ones!
CrowdClinical is ranking hospitals based on Twitter sentiment

<table>
<thead>
<tr>
<th>Rank</th>
<th>Hospital</th>
<th>Twitter Handle</th>
<th>Sentiment Score</th>
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<tr>
<td>1</td>
<td>Children's Hospital Colorado</td>
<td>@childrenscolo</td>
<td>0.703488372</td>
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<td>2</td>
<td>Spartanburg Regional Healthcare System</td>
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<td>4</td>
<td>Arkansas Children’s Hospital</td>
<td>@archildrens</td>
<td>0.625</td>
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Source: http://crowdclinical.com/blog
Conclusion

• You are more in control than you think
• You can impact the way patients’ stories are told in practice and in policy
• You can make sure your organization is embedding listening as a core value
A Summary of How Benefits Were Realized for the Value of Health IT
Questions


Please complete online session evaluation