The Role of Patients’ Stories in Shared Decision Making

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Patients’ Stories are Everywhere

http://youtu.be/W4n9bW-QdgU

http://www.youtube.com/watch?v=BEsste7aXv4
Overview

1. Define patient narratives

2. Describe the impact of narratives on SDM, and provide a taxonomy

3. Demonstrate the use of narratives in SDM
What are patient narratives?

- (narratives, testimonials, or anecdotes) that provide illustrative examples of others’ experiences relevant to the decision.
- Provide the meaning, timeline, and context of an event from the narrator’s perspective.
- An everyday medium that people use to communicate information.
- A valued resource that provides information about the patients’ experience with an illness.

Types of Patient Narratives

• **Perspective**
  – First-person*, 3rd person accounts

• **Form**
  – Discussions between patients, quotes

• **Media**
  – Text in booklets, audio and video, face-to-face

• **Delivery**
  – Person making the decision, actor

Treatment Choices for Men
With Early-Stage Prostate Cancer

3 Men... 3 Different Treatment Choices

"I talked it over with my wife and son. I chose radiation therapy because we thought it was the best choice for my situation."

"When my doctor said he would follow me closely without treatment, I thought he meant that I should give up. But after he explained my stage of cancer, it made sense to me. Now I know that I can decide to have treatment later."

"My wife and I looked at the benefits and risks of each treatment. After talking with several doctors who specialize in prostate cancer, we decided that surgery was the best choice for me."
Dual Processing Theory
How people process information...

System 1 Processing
Experiential-Automatic
- Quick
- Effortless
- Does not require deliberation before action

System 2 Processing
Analytic-Deliberative
- Effortful
- Cognitively demanding
- Requires active reasoning before action

Dual Processing Theory, cont

How people process information...

1) People make choices based on integrating both factual and narrative information,
2) narrative information influences people’s choices directly (system 1) and indirectly via cognitions about risks and values, and
3) the persuasive effect of narratives and factual information varies with reference to the initial perspectives of the decision maker.

System 1 vs System 2 Processing and Optimal Decision Making

**System 1**

Narratives encourage people to employ automatic strategies:

– ie, credibility of the narrator, affect used in the story, other characteristics of the narrator or the message.

Making decisions based on others’ judgments or recommendations!

System 2

Systematic searching for information, reasoning about advantages and disadvantages, making a choice based on one’s own evaluations rather than relying on someone else’s judgments.

Making decisions well!

The Problem...

- Research suggests that narrative information is MORE persuasive than factual information not presented in narrative form.

- Narratives are potentially highly biasing.

## Two World Views of the Role of Narratives in SDM

### The Conservative View
- Narratives are potentially too biasing.
- They promote quick, non-deliberative decisions (i.e., System 1 processes).
- We have no idea how they work.
- Narratives should **not** be used in SDM.

### The Pragmatic View
- Patients want to hear the experiences of others (and will seek others’ opinions).
- Better to provide narratives as part of high-quality decision support.
- Narratives have an important role in SDM and we should investigate how best to use them.

### Table 1: Examples of the Biasing or Facilitating Influence of Facts within Personal Stories.

<table>
<thead>
<tr>
<th>Decision Aid Function</th>
<th>Biasing by Personal Stories</th>
<th>Facilitating by Personal Stories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accurate and Balanced Information</td>
<td>Narrator uses more (or less) value-laden and emotional terms to describe (less) favoured options.</td>
<td>Narrator uses language that helps describe the emotional content of the options and decision.</td>
</tr>
<tr>
<td>Accurate and Balanced Information</td>
<td>Narrator refers to only those facts important to him/her in choosing option A or rejecting option B.</td>
<td>Narrator makes explicit the importance of exploring all options regardless of prior experiences.</td>
</tr>
<tr>
<td>Attention and guidance</td>
<td>The smaller selection of facts used by the narrator to explain his/her choice is easier to process and evaluate.</td>
<td>Guidance on how the narrator went about making the decision.</td>
</tr>
<tr>
<td>Attention and guidance</td>
<td>The story primes/ reinforces selected facts interfering with processing of all facts.</td>
<td>Presents facts in a more accessible way, making them easier to process and recall.</td>
</tr>
<tr>
<td>Patient evaluations/trade-offs</td>
<td>Processing the values and trade-offs important to the narrator when s/he made their choice.</td>
<td>Helps make explicit the role of different patients' values and experiences to make the decision.</td>
</tr>
<tr>
<td>Patient evaluations/trade-offs</td>
<td>Patient opinions about the narrator, and not the story content, used to make the choice.</td>
<td>Provides relevant social reference and/or causal information to help patients reach judgments.</td>
</tr>
</tbody>
</table>

A Taxonomy of Patient Narratives

• **Purpose** (*the “why”*)
  – To inform, engage, model behaviors, persuade, comfort.

• **Content** (*the “about what”*)
  – Decision outcome, experience, process.

• **Valence** (*the “how”*)
  – General expression of satisfaction or dissatisfaction with the process/outcome of a decision.

*Narratives are multidimensional*

<table>
<thead>
<tr>
<th>The Content of Patient Narratives</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcome</strong></td>
</tr>
<tr>
<td>The psychological or physical outcomes associated with a decision.</td>
</tr>
<tr>
<td>“I chose to have a lumpectomy, and constantly worrying about my cancer coming back.”</td>
</tr>
<tr>
<td><strong>Experience</strong></td>
</tr>
<tr>
<td>Provide information about what it is like to have a given disease or treatment.</td>
</tr>
<tr>
<td>“I went to radiation treatment for 5 days a week, for 6 weeks, so I had to miss some work and important events.”</td>
</tr>
<tr>
<td><strong>Process</strong></td>
</tr>
<tr>
<td>Describe how a patient made a particular health care decision – searching for information, weighing options, combining results to form a choice.</td>
</tr>
</tbody>
</table>

Patient Narratives: Experience Narratives

Videos and Social Norms

Uses videos to describe the problem as common and define types of UI

http://www.effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/patient-decision-aids/
Patient Narratives: Experience Narratives

Video documentary

• Decision making about End-of-Life decisions
• 50 patients with malignant glioma recruited from outpatient oncology clinics.
• 90% white; 78% some college/grads
• 76% had advanced directives

## Decisions about End-of-Life Care

<table>
<thead>
<tr>
<th>Levels of Care</th>
<th>Verbal Group - audio descriptions of...</th>
<th>Video Group - verbal content PLUS images of...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life-prolonging care (prolong life at any cost)</td>
<td>CPR, intubation, ICU</td>
<td>Patients in ICU, ventilation, simulated code &amp; CPR, IV meds</td>
</tr>
<tr>
<td>Basic medical care (maintain physical/mental function)</td>
<td>Hospitalization, IV fluids, antibiotics (no life-prolonging measures)</td>
<td>Patients receiving IV antibiotics, medical ward, nasal cannula</td>
</tr>
<tr>
<td>Comfort care (maximize comfort, alleviate suffering)</td>
<td>Medications to relieve symptoms (no hospitalization or life-prolonging measures)</td>
<td>Patient on home hospice care, nasal cannula, medical assistant</td>
</tr>
</tbody>
</table>

Results: Goals of Care Preferences

Fig 3. Participants’ goals-of-care preferences for advanced cancer in the verbal and video groups.

Fig 4. Preferences for cardiopulmonary resuscitation at baseline and after the interventions in the verbal and video groups.

Patient Narratives: Experience/Outcome Narratives

Health Communication Research Laboratory – WUSL

Watch Living Proof: Breast Cancer Survivor Stories

From 2007-2009, researchers at the HCRL captured on video the stories of 49 African-American breast cancer survivors and their family members. The result was 50 hours of poignant, informative and uplifting stories of survival. Personal stories are often the most effective way to communicate about breast cancer, and Living Proof—the 22-minute video we produced using these stories—shows why. It offers a compelling demonstration of the power of narratives in cancer communication.

From the Director: more about survivor stories here

http://hcrl.wustl.edu/
Narrative vs Informational Videos to Increase Mammography

- Compared two videos to promote mammography screening among low-income African American Women.
- Contain the same factual content.
- *Living Proof* contained stories from AA breast cancer survivors (narrative videos).

Kreuter et al, Pat Educ Counsel 2010.
Main findings

• Narrative video subjects reported:
  – Enhanced recall, better “like” of video, reduced counter-arguing, increase discussions with family members.
  – Fewer barriers to screening, more confidence.
  – No overall difference in mamm. rates, BUT sign differences for group with less than high school education (65% vs 32%).

Kreuter et al, Pat Educ Counsel 2010.
Patient Narratives: Process Narratives

Normative Messaging

Uses quotes with the goal of changing attitudes through messages

http://www.effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/patient-decision-aids/
Patient Narratives: Process Narratives

ACS “Prostate Cancer Informed Decision Making Video for Patients”

(note system 1 and 2 elements)

Patient Narratives: 
Process Narratives – new approaches

Entertainment
Education

Process narratives using telenovelas to engage patients in the decision-making process

Supported by Award Number R21CA132669 from the National Cancer Institute.
Health-Related Narratives as Entertainment Education
Entertainment-Education defined

“Entertainment-education (EE) is the process of purposely designing and implementing a media message to both entertain and educate, in order to increase audience members’ knowledge about an educational issue, create favorable attitudes, shift social norms, and change overt behavior.” – Singhal & Rogers, 1999, 2002
Colorectal Cancer Screening: A Story of Choices

Design Requirements

- For use with screen-eligible patients
- Use in clinical setting
- Linear
- Video-based
- Delivered on laptops
- Low literacy design considerations
- Entertainment-based
- Culturally-tailored
- Spanish and English language versions
### Sample Key Message Map

<table>
<thead>
<tr>
<th>Key Message</th>
<th>Covered in Module(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colorectal cancer can be a life threatening disease.</td>
<td><strong>TS1:</strong> Daughter Lazette tells parents her father-in-law hospitalized and could die of CRC.</td>
</tr>
<tr>
<td>Colorectal cancer is the second leading cause of cancer-related deaths in the United States.</td>
<td><strong>LM1:</strong> Covered verbatim <strong>TS2:</strong> Wife Audrey tells husband Gerald this fact while showing him a brochure she got from the health minister at church.</td>
</tr>
<tr>
<td>Colorectal cancer testing is easy to do.</td>
<td><strong>TS5:</strong> Doctor says “Colorectal cancer screening is actually pretty easy.”</td>
</tr>
</tbody>
</table>

*TS* = telenovela scene

*LM* = learning module
SCENE ONE:
Morning, int., at KITCHEN Island. Lazette, 29, shows her mother Audrey, 49, how to use a new COMPUTER. Her father Gerald prepares two CUPS OF COFFEE at the counter behind them.

Lazette: ... so on this one, you put the word here, and then click. This search engine gives really good results.

Audrey: Honey, this is not an engine, Ok? This engine isn’t taking me anywhere.

Lazette: Momma, can you keep Deirdre this afternoon?

Audrey: She’s my granddaughter, of course

Lazette: I have to go see Daddy Williams.

Gerald: You talking about me?

Lazette: (smiles) No, my other Daddy. Henry’s father is in the hospital.

Audrey: In the hospital? What happened?

Lazette: Well, he’s been complaining about constipation for a while, and then he was seeing blood in his stool, and he’s in his sixties, never got his colon or his rectum tested, and when he finally did get it looked at...

Gerald: (clears his throat uncomfortably)
Conclusions from research on patient narratives

1. Well-designed PtDAs that contain the active ingredients of a quality decision do not necessarily benefit from narratives.

2. Narratives are particularly attractive to some patients (e.g., low health literacy).

3. Narratives affect the motivational and emotional elements associated with attending to information.
Research Agenda in Narratives

• **Process narratives**
  – Do they improve SDM, for which patients?

• **Experience narratives**
  – Are they more effective at communicating factual information than text?

• **Valence**
  – How do patients react to “positive” vs “negative” messages?
Research Agenda in Narratives

- **The “Narrator”**
  - How do different characteristics of the story teller impact SDM?
  - How important are these characteristics for different narrative types?

- **Social media and the web**
  - How does social media impact the role of narratives in SDM?
  - How balanced/biased are publicly available narratives? How can we address this bias in SDM?
Thank you
DECISION AID TOOL

Adjuvant Endocrine Therapy for Hormone Receptor-Positive Breast Cancer

This booklet is what is often called a decision aid. The goal of decision aids is to help patients better understand their treatment choices and to help them make the best medical decision possible for their situation.

This decision aid is for women who are post-menopausal and who have hormone receptor-positive (ER+ and/or PR+) breast cancer and are trying to decide whether or not to take adjuvant (after surgery) endocrine therapy and what type of endocrine therapy to take. The goal of this decision aid is to help patients and doctors talk to each other in order to make decisions about treatment. It is based on recommendations from the American Society of Clinical Oncology’s updated Clinical Practice Guideline on adjuvant endocrine therapy. Use of this decision aid is voluntary.
Adjuvant Endocrine Therapy
After you have surgery, radiation, and/or chemotherapy, you should think about whether or not to take adjuvant endocrine therapy. Adjuvant endocrine therapy is medicine only for women with ER+ and/or PR+ breast cancer. There are two basic types of adjuvant endocrine therapy: tamoxifen and aromatase inhibitors. Tamoxifen has been proven to lower the chance of breast cancer returning and helps women with early-stage breast cancer live longer. Tamoxifen is a pill that is taken every day. Aromatase inhibitors lower the amount of estrogen in the body. There are three different aromatase inhibitor medicines: anastrozole, letrozole, exemestane; but they all work the same way. Aromatase inhibitors are also pills that are taken every day.

Options:
1. Tamoxifen
2. Aromatase inhibitors
3. Tamoxifen + aromatase inhibitors
BENEFITS

The first set of pictographs, below, show the chances of breast cancer coming back in the same breast in 5 years.

Chances of breast cancer coming back (in the same breast your cancer was in)

1. Out of 100 women taking tamoxifen for 5 years, 17.4 had breast cancer return.

2. Out of 100 women taking an aromatase inhibitor for 5 years, 16 had breast cancer return.

3. Out of 100 women who took tamoxifen and switched to an aromatase inhibitor, 16.7 had breast cancer return.

Therefore, the number of women who had breast cancer come back was quite similar with all three treatments. There were small differences favoring the use of an aromatase inhibitor as either first treatment, or after tamoxifen.
Bone fracture

After menopause, a woman can lose bone and her bones may be more likely to break. Aromatase inhibitors may slightly increase the chances of a bone break compared to tamoxifen.

In a woman who is postmenopausal, tamoxifen may help prevent osteoporosis (fragile bones).

**Chance of getting a bone fracture in 5 years**

1. Out of 100 women taking tamoxifen for 5 years, about 7 women (7.3) had a bone fracture.

2. Out of 100 women taking an aromatase inhibitor for 5 years, about 10 women (9.8) had a bone fracture.

3. Out of 100 women who took tamoxifen and switched to an aromatase inhibitor, about 10 women (9.4) had a bone fracture.

Therefore, about 2 to 3 fewer women (2.1-2.5) taking tamoxifen had a bone fracture, compared to those taking an aromatase inhibitor.
The following pages are to help you think about what type of adjuvant therapy (for hormone receptor-positive (ER+ and/or PR+) breast cancer) to have after you have talked to your doctor. You may want to do this on your own or with someone you trust.

Your treatment options may include:
- Taking tamoxifen (a type of hormone therapy)
- Taking an aromatase inhibitor (another type of hormone therapy)
- Taking tamoxifen and an aromatase inhibitor together

### Weighing Your Options

<table>
<thead>
<tr>
<th>BENEFITS:</th>
<th>How much does this matter?</th>
<th>How likely is this to happen to you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lowering the chances of breast cancer coming back</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Lowering the chances of getting breast cancer in the other breast</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>You can add another benefit here:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RISKS:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood clots</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Bone fracture</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Endometrial cancer</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>Hot flashes</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4 5</td>
</tr>
<tr>
<td>You can add other concerns here and below:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4. Plan the next steps
Consider planning your next steps based on your needs:

a. If you feel you do not have enough support and/or if you feel pressure from others—you may want to look for other support. Your doctor, hospital, or clinic may be able to refer you to others who could help you find additional support.

b. If you feel you do not have enough facts about adjuvant endocrine medicines, you may want to get more. For example, you could visit cancer.net (www.cancer.net).

Please use the space below or another page to write any questions or concerns you have:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
A little theory….

An integrated model of health behavior adapted for colorectal cancer screening

External variables
• Demographics
• Past screening behaviors
• Etc.

Beliefs about CRCS efficacy ➔ Attitudes toward CRCS

Normative beliefs & motivations to complete CRCS

Norms regarding CRCS*

Intentions ➔ Completion of CRCS

Beliefs about self-efficacy

Self-efficacy to complete CRCS*

*EE can be helpful in modeling these behaviors

Adapted from Frosch et al., Implementation Science, 2009.
Screenshots of Telenovela and Learning Modules

Telenovelas to promote engagement

Animations to communicate key learner content

Volk – PI (NCI)
Screenshots of Test Attributes

Discomfort

- FOBT
- Flexible Sigmoidoscopy
- Colonoscopy

Complications

- FOBT: None
- Flexible Sigmoidoscopy: Possible tears or bleeding
- Colonoscopy: Possible tears or bleeding

Accuracy

- FOBT: GOOD
- Flexible Sigmoidoscopy: BETTER
- Colonoscopy: BEST

Frequency

- FOBT
- Flexible Sigmoidoscopy
- Colonoscopy

(Chart showing frequency over years)