2012 Patient Experience Webinar Series

The Role and Perception of Privacy and its Influence on the Patient Experience

Presented by Susan Mazer, PhD, MA-HOS, MA, President and CEO, Healing Healthcare Systems, Inc.

Dial-in Number: 1-877-668-4493
Passcode: 804 807 806
Defining Patient Experience

The sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.

- The Beryl Institute
Upcoming Patient Experience Regional Roundtable Event

Orlando – November 8

Host site:

Make Connections
with other patient experience leaders.

Take Away New Ideas
to enhance your patient experience efforts.

Leave with a Plan
to immediately impact your organization.

Space is Limited. Register Now.
Housekeeping

- All participant phone lines are muted.
- The presentation will run 45-50 minutes with about 10-15 min for Q&A.
- Q&A will be conducted through the chat function. Please submit questions to the host for a facilitated Q&A after the presentation.
- Webinar materials and session recording will be available for all attendees. (an email will notify you when available with the appropriate link)
- A post-webinar survey will be distributed following today’s session.
The Role and Perception of Privacy and its Influence on the Patient Experience

Presented by Susan Mazer, PhD, MA-HOS, MA, President and CEO, Healing Healthcare Systems, Inc.

This session is a follow-up to the recent white paper from The Beryl Institute that explores the results of a significant study exploring the implications of patient perceptions of privacy and the impact this has on the overall patient experience. It shares perceptions of patients as they reflected on what happened to them during care. The insights move us beyond the limiting constraints of considering privacy simply as a regulation, to better understand what ultimately matters to patients at the bedside as they engage in healthcare and create their own perceptions of experience. It provides practitioners a new lens through which to examine privacy and to explore the impact that can be created in every healthcare encounter. The webinar will take a deeper look into the actual experiences as described in this study translated into bedside events that may occur at your own hospital. There will be time for discussion and questions that will move the issues at hand into the core of improving the patient experience.
HIPAA AND BEYOND: UNDERSTANDING AND RESPONDING TO PRIVACY NEEDS OF RESIDENTS, STAFF, AND FAMILIES

Susan E. Mazer, PhD
Healing HealthCare Systems
October 25, 2012
I AM AN ADULT CHILD OF THREE PARENTS WHO DIED UNDER HIPAA REGULATIONS.
CAREGIVING OCCURS WITHIN THE PRIVATE LIFE-WORLD OF A PATIENT.
PRIVACY IS A CLOSED-DOOR...
PRIVACY IS BEING ALONE...
PRIVACY IS INTIMATE...
PRIVACY IS NOT ALWAYS PRIVATE...
PRIVACY IS A MOMENT...
PRIVACY IS WATCHED...
PRIVACY IS SET ASIDE...
PRIVACY CAN BE TRADED...
PRIVACY CAN BE LIVED IN PUBLIC...
IN SO MANY WORDS, PRIVACY IS...

- Power and will to control one’s destiny (Erikson): **Autonomy**
- Control over one’s own person (Warren/Brandeis): **Liberty**
- Control information about one’s self (Westin): **Private property**
- Right to withhold access to self (Simmel): **Secrecy**
- Physical environment defined and controlled by Self (Altman): **Physical space**
PRIVACY IS...

- Demanded
- Denied
- Designed
- Defended
- Defined
WHAT IS BASIS FOR PATIENT PRIVACY?

Whatever I see or hear in the lives of my patients, whether in connection with my professional practice or not, which ought not to be spoken of outside, I will keep secret, as considering all such things to be private.

Hippocratic Oath, 4\textsuperscript{th} Century B.C.
THE PARADOX OF PATIENT PRIVACY

- Being a patient requires a redrawing of privacy boundaries
- Treatment/caring requires surveillance/observation/intrusion
- Privacy as lived by an individual who, to their own values, has none, takes on new and unspoken meaning.
THE PARADOX OF PATIENT PRIVACY

How do patients make meaning of their privacy during a hospitalization: A retrospective
METHODOLOGY:
PHENOMENOGRAPHY

- Looks for the *variations* in the ways *meaning* is derived from a phenomenon
- Acknowledges the uniqueness of the human experience
- Is not assumed to be generalizable...but to reveal insights about the human condition.
RESEARCH DESIGN

- 14 individuals from two communities
- Signed informed consent
- 63 - 96 years of age
- Hospitalized a minimum of one night within the last 36 months
- Able and willing to discuss their experience
- Open-ended, guided interview
- Interview lasted until participant was complete
- Familiar setting to the participant
13 ASSOCIATED THEMES/ASPECTS

“What” patients perceive as patient privacy

+ Autonomy, ownership
+ One’s business (my business is my business)
+ Control over my own body
+ A physical place and space.
+ Dangerous
+ Personal
+ Lonely
ASSOCIATED THEMES/ASPECTS

“How” privacy is provided or evidenced.

- Not being subjected to anyone else’s sounds/words/discussions
- Being alone/left alone
- Hiding secrets, being ashamed of something
- Not telling or having to tell anyone anything
- Not responding or having to respond to anyone
- Being in control of one’s life
- Deciding if privacy is relevant or irrelevant
CATEGORIES OF MEANING

(1) Self-interest: core of a person
  - Privacy is autonomy, ownership
  - Privacy is one’s business (my business is my business)

(2) Protection of Self from being subjected to others
  - Privacy is not having to tell anyone anything, not having to respond to anyone
  - Privacy is not being subjected to anyone else’s sounds/words/discussions

(3) Defense of Self in relationship to the other
  - Privacy is being in control of one’s life
  - Privacy is control over my own body
(4) Safe-guarding of Self from invasion by the other
- Privacy is a physical place and space.
- Privacy is being alone/left alone

(5) Self in relationship to perception of others’ judgment
- Privacy is hiding secrets, being ashamed of something

(6) Self about Self-perception of circumstances
- Privacy is dangerous
- Privacy is personal
- Privacy is lonely
- Privacy is not always important
MASLOW: HIERARCHY OF NEEDS

Human motivation theory

- Each need motivates behavior.
- As each need is satisfied, the next need is experienced.
HIERARCHY OF PRIVACY NEEDS

Wholeness: Has control over own life and boundaries
Well enough to want autonomy and self-reliance
Interdependence with family and friends
Hospital provides meets expectations for care
Physical discomfort and instability

Privacy/Openness balance; Privacy needs are dormant unless violated
Privacy is very important
Privacy begins to matter
Privacy has little importance
Privacy is irrelevant

Level of Acuity as related to Privacy needs
WHAT DID THE DATA REVEAL?

- Privacy is a both an assumption and a defense
- Privacy is a need revealed and defined only when unsatisfied.
- Privacy boundaries are most often declared when crossed or in retrospect
- Risks that result from extended lack of privacy include learned-helplessness and dependence.
- The autonomy that lives within personal privacy is more critical in evaluating patient privacy
IMPLICATIONS FOR THE PATIENT EXPERIENCE AND PRACTICE

- The person who does the caring must understand its privilege.
- Privacy cannot be managed at the top; must be valued within the culture.
- Understand preferences of family and of resident: ask about privacy preferences.
- Know both Risks or Benefits.
HIPAA deals with medical records: Residents are not their records.

Families need to know privacy practices at the bedside.

Staff privacy: How much to share.
HIPAA AND BEYOND: UNDERSTANDING AND RESPONDING TO PRIVACY NEEDS OF PATIENTS, STAFF, AND FAMILIES

Susan E. Mazer, PhD
Healing HealthCare Systems
October 25, 2012
Upcoming Webinars

November 1
Exploring Bright Spots: Learning from the Nation's Leaders in Providing Exception Patient Experiences
Presented by Kim Bordenkircher, CEO, Henry County Hospital; Teira Gunlock, Client Education Consultant, Professional Research Consultants, Inc.; and John Gnida, Director of Client Education, Professional Research Consultants, Inc.

November 6
Achieving Patient Experience Excellence through Cultural Transformation*
Presented by Rhonda Dishong, Director of Customer Experience Design, Memorial Hermann and Qaalfa Dibeehi, Chief Operating and Consulting Officer, Beyond Philosophy

December 4
You Cannot Manage Perceptions in the Same Way You Manage Outcomes*
Presented by Fred Lee, Author, If Disney Ran Your Hospital
The Beryl Institute is the leading community of practice for individuals and organizations committed to improving the Patient Experience. Through its efforts, the Institute:

- Engages over 10,000 members and guests from over 25 countries
- Produces two monthly e-news features *Patient Experience Newsl ink* and *Patient Experience Monthly*, sharing leading policy and practice around the patient experience
- Publishes 6-8 comprehensive white papers per year and offers accompanying webinars
- Supports 10 patient experience research grants
- Conducts the leading benchmarking study on the state of patient experience
- Hosts the annual Patient Experience Conference and Regional Roundtable gatherings

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Thank you for participating!

Please keep your eyes open for a post-webinar evaluation coming soon...

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