

Patient Participation in Evidence-Based Healthcare

Kevin Bradford, Assistant Professor
Clinical Information Librarian
Medical College of Georgia
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Introduction

- “Patient Empowerment:” Consumer access to medical research brings new expectations and concerns (e.g., where to look, how to evaluate)
- EBP impacts the literature used to support clinical decision-making as well as the decisions consumers make about their health care
- The ready availability of healthcare information requires that:
 - New criteria be developed for helping patients and families become more health information literate
 - A new format devoted to translating and presenting systematic research be made accessible in a language appropriate for the general public

Patient Empowerment



- In the not-too-distant past, patients seeking information were limited to the resources provided by a health care professional (e.g., paternalistic model of healthcare).
- Roots of American medical consumerism grew out of two movements and set the stage for today's consumer health:
 - (1) Ralph Nader's consumer activism of the 1960s
 - (2) Women's Movement of the 1970s
 - *Our Bodies, Ourselves* [1]

Patient Empowerment

- Additional Influences Shaping Consumer Healthcare:

- Karen Ann Quinlan and the Right to Die (1976)

- The idea that patients and their families have the preeminent right over clinicians to take charge of their medical decisions



- The era of Managed Care (1980s-Present)

- Medicine's shift from a profession to a business
 - Change in the role and practice of clinicians
 - Scarcity of medical dollars transfers the burden of making intelligent healthcare decisions away from clinicians and towards patients and families

Patient- and Family-Centered Care

- Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers.
- **Core concepts of patient- and family-centered care:**
 - **Dignity and Respect**
 - **Information Sharing [Electronic Medical Record]**
 - **Participation**
 - **Collaboration**

Source: Institute for Family-Centered Care, online at
<http://www.familycenteredcare.org/faq.html>

Patient- and Family-Centered Care

■ Research

- There has been an increase in the literature on patient- and family-centered health care. The focus has been primarily on the partnerships between patients, families, and providers at the clinical level.
- MCG's Center for Patient- and Family-Centered Care's Research Interest Group:
 - Interest group sessions offer an opportunity to interact with others who are expanding PFCC scholarship and research. All five schools at MCG - Allied Health Sciences, Dentistry, Graduate Studies, Medicine and Nursing- are represented.
 - <http://www.mcg.edu/centers/cpfcc/Research.html>

EBP and its Impact on the Literature

- The Descriptive Study (Case Report)



- This type of literature describes the approach to a new event or condition
 - Defined as: *“Concerned with and designed only to describe the existing distribution of variables, without regard to causal or other hypotheses.”* Grimes, Schulz [2].
- Descriptive studies consist of two main categories:
 - Those dealing with individuals
 - Those dealing with groups

EBP and its Impact on the Literature

- Good descriptive reports answer five basic questions: who, what, why, when and where:



- A clustering of unusual cases in a short period of time may often herald an epidemic.
- Unusual cases make it hard to feel confident to generalize from the experience of a particular case.
 - Studies without a comparison group do not allow conclusions about causation.
- Descriptions of case studies act as catalysts for further research by more systematic methods (e.g., randomized controlled trials, systematic reviews).

Consumer Access: New Expectations and Concerns

- Patient Empowerment
 - Patient perspective is missing from the Clinical Practice Guidelines:
 - Integrate patient preferences into guidelines (Krahn, Naglie [3]):
 - * Finding patient-related evidence (e.g., qualitative literature)
 - * Using guidelines in individual decision-making
 - * Evaluating guidelines with preferences in mind
 - * Including patients in guideline development

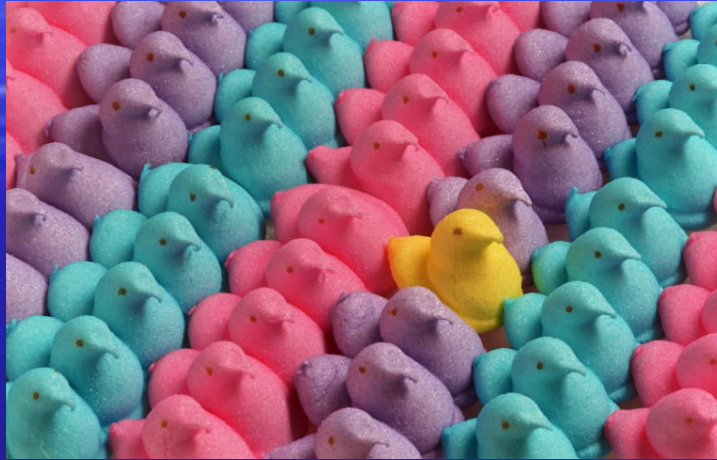


Consumer Access: New Expectations and Concerns

- Expanding the role of the patient (“Shared Decision-Making”)
 - In the new paradigm of “patient as partner,”
 - Patient responsibility for accessing information and forming questions [AHRQ’s “Questions are the Answer”]
<http://www.ahrq.gov/questionsaretheanswer/questionBuilder.aspx>
 - Creating teams (including patients) “*with the authority to act and transform care*” [IHI, “Transforming Care at the Bedside”]

Consumer Access: New Expectations and Concerns

- Explosion of Internet Websites:



Which site to trust?

– Health Literacy: *"The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."*

- Healthy People 2010:

<http://www.cdc.gov/nchs/hphome.htm#Healthy%20People%202010>

Consumer Access: New Expectations and Concerns

- Providing patients with the best guidance requires special skills beyond clinical care. Health care professionals need to be able to both perform AND teach the following skill sets:



- 1. Locating information that meets rigorous research criteria
- 2. Critically analyzing the findings and deciding whether they are applicable to the individual patient

Measuring Quality Information for Treatment Options

- Clinical Effectiveness

- EBP involves the constant evaluation of the most effective treatments for a health condition
- Often entails replacing established treatments with new or different ones
- The acknowledgement of uncertainty about the most effective treatment

- Consumer Choice

- Shared decision-making: patients and families work together to find the best treatment choice.

Measuring Quality Information For Treatment Options-Guidelines for the CONSUMER

- Is the publication reliable
 - Clarity of aims
 - Sources of information
 - Date of publication or revision
 - Bias
 - Additional Sources
 - Areas of uncertainty
- Quality of information
 - Description of how treatment works
 - Benefits of treatment
 - Risks of treatment
 - Results of no treatment
 - Other treatment choices

Consumer Healthcare: Selected Sources

- [Cancer.gov](#)
- [Centers for Disease Control and Prevention \(CDC\)](#)
- [familydoctor.org](#)
- [Georgia Health Go Local](#)
- [healthfinder](#)[®]
- [Kidshealth](#)[®]
- [Mayo Clinic](#)
- [MedlinePlus](#) ([English](#) | [Spanish](#))
- [NOAH: New York Online Access to Health](#)
- The [Consumer and Patient Health Information Section](#) (CAPHIS) of MLA evaluates web sites based on the following criteria: credibility, sponsorship/authorship, content, audience, currency, disclosure, purpose, links, design, interactivity, and disclaimers.

Organizations

Agency for Healthcare Research and Quality

- <http://www.ahrq.gov/>

Center for Healthcare Design

- <http://www.healthdesign.org/>

Institute for Healthcare Improvement

- <http://www.ihp.org>

The Institute for Family-Centered Care

- <http://www.familycenteredcare.org/>

The National Working Group on Evidence-Based Healthcare

- <http://www.evidencebasedhealthcare.org/>

References

- [1] Boston Women's Health Collective, *Our Bodies, Ourselves* (1973).
- [2] David A. Grimes, Kenneth F. Schulz. *Descriptive Studies: what they can and cannot do*. *Lancet* 359:145-148.
- [3] Murray Krahn, Gary Naglie, "The next step in guideline development: incorporating patient preferences" *JAMA* 300(4) 436-38.
- [4] Deborah Charnock, comp., *The Discern Handbook*, comp. University of Oxford and the British Library (1998), online at: www.discern.org.uk/