

CHALLENGES IN PROVIDING DECISION SUPPORT TO PATIENTS

Jack Fowler

Informed Medical Decisions Foundation

(At least) 4 steps needed to support shared decision making

- 1. Identify patients in decision windows
- 2. Get information to them in form that is useful
- 3. Have patients expose themselves to the information they need
- 4. LEADING UP TO THE MAIN OBJECTIVE: Having patients (now informed) actively involved with providers when decision is made

Identify patients in decision windows in advance of when decisions are made

- THIS TURNS OUT TO BE HARD, AND IT IS A STEP FOR WHICH GOOD EMRS CAN POTENTIALLY BE HELPFUL
- 1. Easy for cancers, where a bad biopsy leads to treatment decisions
- 2. Should be doable for elective surgery, particularly if a referral from primary care to specialist happens before decision is made. However, often a judgement is needed about reason for referral, diagnosis and how close patient is to being in a decision window
- 3. Should be doable for screening tests, but requires pre-visit efforts

Identifying patients (cont'd)

- 4. . Hard for prescription meds, for which decisions usually/often made during visit
- 5. Hard for diagnostic tests, because decisions often made during visits'
- 6. Hard for most interventions occurring during urgent care events

One thing we know

- Relying on physicians to initiate decision support tools is not very reliable
- Having clinician support staff involved helps a lot
- Great opportunity for electronic support, but something has to be entered into record by someone to indicate there is a decision window, and often some additional judgement is needed to correctly identify decision opportunity and kind of info that is most relevant

Get information to patients in timely way

- Length and complexity of information that is needed
- Form or medium in which information is cast
- Delivery strategy

Length and complexity of info needed

Lists of pros and cons

Lengthier presentation of evidence

Statistics on risks and benefits

Graphics to help patients understand condition and
Interventions

Patient interviews to provide perspectives and rationales

Form or medium

- Paper
- Computer screen
- DVD

Delivery strategy

- Paper: show in office, hand to patient in office, mail, send via e-mail to print out
- DVD: watch in office, hand out in office, mail to home, stream on web
- Internet: show in office, patient retrieves on own computer

Getting patients to look or review

- In office is pretty easy—need to schedule time
- At home, depends greatly on topic and how and when it is presented

Integrating an informed patient into decision making

- Key problem is getting patient to become informed BEFORE meeting with provider when decision will be made
- For cancer, there is a window between biopsy and meeting with provider that can be used to inform patients
- For referrals to consider a specific intervention, there is a window to inform patients
- When tests, like cancer screening, are coming up, patients can be given information before meeting with provider

Integrating an informed patient into decision making

- Unanticipated decisions made in office, such as prescriptions and some diagnostic tests, require physicians to expose patients to information during visit, which seldom happens and very much limits amount and kind of information presented
- Protocols can be developed whereby patients get informed after visit then interact by phone with coaches or other providers, or make decision on their own

Integrating an informed patient into decision making

- One of the real potentials for EMR is to provide a way to ensure key patient input, such as what patient knows and what patient values, is collected and given to provider
 - ---THAT IS ONE WAY TO AMPLIFY THE PATIENT'S VOICE

Examples of success

- Group Health in WA
- UCSF Breast Cancer Center
- Secure Health in Wisconsin
- Dartmouth Breast Cancer Center

Also, two things we have learned that are not barriers

- 1. PATIENTS REALLY LIKE GETTING GOOD INFORMATION AND BEING INVOLVED IN DECISIONS
- 2. DOCTORS WHO HAVE USED DECISION AIDS ARE VERY POSITIVE ABOUT THEM, THO THOSE WHO HAVE NOT ARE OFTEN NEGATIVE
- HARD TO SEPARATE CHICKEN AND EGG—BUT DOCTORS WHO USE DECISION AIDS SAY IT DOES NOT TAKE MORE TIME TO MAKE DECISIONS WITH AN INFORMED PATIENT AND DECISIONS ARE BETTER

Summing up challenges—and issues about which we need more studies

- Identifying patients at right time
- Getting right info to patients in form that is appropriate
- Getting patient to review and absorb information
- Integrating an informed patient into decision making process

THANK YOU