Faculty Disclosure

The following presenters have listed no financial interest/arrangement that would be considered a conflict of interest.

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Engaging in Self-Care Through Use of a Personal Electronic Health Record

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Objectives

1. Describe how patient-centered health information technology can enhance patient engagement in self-care management, communication with care providers, and improve health outcomes.
2. Illustrate the use of an electronic personal health record in the management of health information by patients with type 2 diabetes.
3. Describe lessons learned that can aid in enhancing patients’ participation in their care.
Patient-Centered Health Information Technology

- Personal health records (PHRs)
- Patient portals
- Mobile health applications

Personal Health Records

- Personal health records (PHRs) are patient-controlled, electronic tools for patients to maintain a comprehensive health history.1
  - PHR use has the potential to:2-6
    - Enhance patient knowledge
    - Improve self-care behaviors
    - Facilitate shared decision-making between patients and their health care providers
  - Stage 2 Meaningful Use Criteria just released7
    - Requirement to provide patients with access to their health records

Personal Health Records

- Types:
  - Provider-tethered
  - Payer-tethered
  - Standalone

PHRs and Diabetes

- To explore how patients with type 2 diabetes use a personal health record (PHR) to manage their diabetes-related care.

PHRs and Diabetes

- Why a standalone?
  - Accessibility
  - Not well-studied

- Microsoft HealthVault (http://www.healthvault.com)
  - No-cost commercial product
  - Accessible anywhere with Internet access
  - Patients received a standardized training program
  - Patients were given access to the PHR
Study Design

• This study used an exploratory qualitative design.

• Participants were purposefully selected using a homogeneous sampling approach.

• All patients using a PHR as part of a larger mixed methods study were included.

Study Population

• Patients with type 2 diabetes (N=70)

• Enrolled from two internal medicine clinics in a Midwest metropolitan city

Data Collection and Analysis

• A semi-structured interview protocol was used to solicit information about how and why patients used the PHR.

• Interviews were audio recorded, transcribed, and analyzed using a systematic process to fully develop codes, patterns, and themes.

• A memoing procedure was used in which initial codes are made using in vivo coding.

• These in vivo codes were used to develop an overall description of the data centered on patients’ use of the PHR to manage their diabetes-related care.

• Descriptions were consolidated into categories, and once relationships between categories emerge, overarching themes are developed.

• The study is ongoing.

Results

• A total of 59 participants have completed interviews

• 36 females and 23 males

• Average age: 57 years old

• Average of 12 years since initial diagnosis of type 2 diabetes

Health Information Tracked in the PHR

• Hemoglobin A1c
• Blood glucose
• Blood pressure
• Cholesterol
• Family history
• Health care providers’ contact information
• Height
• Immunizations
• Laboratory results
• Medications
• Medical conditions
• Procedures
• Weight

Themes

• Difficult to use
• Situational access issues
• Life got in the way
• Out of sight, out of mind
• Double tracking
• Complete and accessible record
• Increased awareness
Difficult to Use

- Participants shared difficulties that influenced their use of the PHR.
- These problems started with logging in and continued through data entry.
  - One participant described the trouble she was actively having in logging in to the PHR, "I'm trying to sign in right now, I can't even remember my ID, isn't that terrible?"
  - Many participants felt that the PHR could be simplified, with one participant noting that it "takes too much time and is way too frustrating."

Life Got In the Way

- Participants shared how a variety of issues led to sporadic use of the PHR.
- These issues included:
  - Being displaced because of Missouri River flooding and not finding the time to use the PHR
  - Having to deal with family members' health problems
  - Personal illness
  - Family obligations
  - "Life just got crazy!!"

Out of Sight, Out of Mind

- Many participants commented that their daily life led to them forgetting to use the PHR at all.
  - "I never got into the habit of doing it. It was out of sight, out of mind."
- Not part of daily routine
- Feeling lazy
  - "It required effort on my part."

Complete and Accessible Record

- Participants found it useful to have all of their health information in one spot.
  - "I use it as a general overall record of my health."
  - "Just knowing that there is a record there that I can go to all the time."
  - "If something happens and I needed medical records, now they can get it."

Double Tracking

- The PHR did not replace currently-used tracking tools... Essentially double tracking.
  - Excel file
  - Written records
  - Memory
  - Print-outs
  - Glucometer
  - "...being able to average and get my blood sugars in Excel is what I am used to."
  - "I put in a few things at the beginning, but I usually just keep it on paper. It's easier for me to just write it on paper near where I test my blood sugar."
Increased Awareness

- Participants became more aware of changes in their diabetes-related care as a result of PHR use.
- They liked a feature in the PHR that created a visual chart of their progress.
- “...the graphs. It gives you a visual representation of what your readings are doing.”
- One participant described viewing her progress over time, “I think it’s more of a reminder when I go back in those numbers. It isn’t like you take them and forget what they are...I go back and look at them and, ‘Oh, wait a minute, I was kind of messing up there, I should do better’.”

Suggestions for PHR Improvement

- Providing the normal laboratory parameters (“I was trying to enter lab results and it wouldn’t accept values unless I knew the letters afterwards”)
- Allowing patients to link their medications and blood sugar levels within the PHR
- Providing reminder contacts to use the PHR
- Overall, “It has to be easy for us to understand and use and quick and simple. And usually computer programs aren’t like that”.

Lessons Learned

- Potential for standalone PHRs to connect across various health care settings and providers
- Requires provider engagement even though it is a patient-centered technology
- Nurses are in a key role to:
  - Encourage use of PHR and portals
  - Use information from PHR during intake assessments
- Patient empowerment and advocacy

Conclusions

- Findings suggest that patients do not perceive the PHR as a “better” way to track health information; rather it is an alternative to their currently-used tracking tools.
- While there are recognized benefits to PHR use in enhancing patients’ awareness of their diabetes-related care, there are also many barriers that inhibit effective PHR use.
- This viewpoint illustrates the role that current standalone PHRs may play in patients’ record-keeping behaviors.

References: