Navigating the Health Care System

A Health Literacy Perspective Through the Eyes of Patients

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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
Purpose and Process

• To gain patients’ perspectives on...
  – Navigating health care services
  – Interacting with medical providers and staff
  – Understanding health information
  – Self-care

• Understanding their perspective helps us improve our practices

• How?
  – Document and describe the process of scheduling and attending a primary care visit

• Where?
  – UNC Internal Medicine Enhanced Care Clinic

• Who?
  – New patient: Ashley Hink
  – Returning patient: Larry Holt
Patients

- Ashley Hink
  - 25 years-old
  - MPH Student
  - Researcher, health educator
  - Has difficulty sleeping
  - For the purpose of the visit, she claims to have high blood pressure and no insurance

- Larry Holt
  - 58 years-old
  - School Custodian, father and grandfather
  - Has diabetes, hypertension and chronic shoulder pain
  - Insured through BCBS State Health Plan
First steps

I referred to a pamphlet about the Internal Medicine phone system to help me schedule my appointment. It was easy to understand, and I knew exactly which option to select.
Scheduling confusion

It took a total of 2 calls, 4 selected options, 2 connections, 1 voicemail message, 1 call-back and a final conversation with an Enhanced Care staff member to get my appointment. Fortunately, I was able to see Dr. Malone within one week.
Paperwork, and lots of it

As a new patient, I am required to fill out a seven-page personal health summary – most of which is very straight-forward and easy to fill out.
Health History Form

- Seven pages inquiring about social and medical history
- Generally easy to follow and read
  - Some medical terms have common names in parenthesis
    - Anemia (low blood)
- Some of the answer options are not appropriate for the question (multiple choice vs. fill-in)
- Often resort to qualifying answers

VD – not spelled out, examples are hard to read for those with low literacy
Release of Medical Information

- No explanation or guidance
- Technical/legal language, written at a high grade level
- Must infer what information is needed
  - I authorize _____ to release to _____ the medical records of _____.
- I decided to leave this blank for now, and will fill it out if requested by the provider
Reminders and homework

In addition to my appointment reminder in the mail and over the phone, I receive an explanation of my upcoming appointment to the blood pressure clinic. It asks me to bring all of my medicine and to take my blood pressure before coming in.
Requested BP Check

1/10/09 Before giving blood:

108/74

1/11/09 With home monitor:

120/83
Made it

The UNC Ambulatory Care Center is home to 8 separate clinics. While the sign is hard to read from the road, it lets me know I’m in the right place.
Direction and assistance

While looking at the sign that directs patients to the correct floor, a security guard greets me from the information desks and asks if I need help.
Check-in

A staff member checks me in and I’m pleasantly surprised to find out that I have no additional paperwork to fill out, nor do I have to wait. I was asked if I had health insurance – I turned around after saying ‘no’ only to see people listening to my conversation.
Waiting...

I paused at the door in attempt to follow directions. After waiting a while a staff member told me to walk to the end of the hall.
Weight and vitals

A cheerful nurse quickly gets my weight, heart rate and blood pressure.
Excellent physiological acting

My first blood pressure reading was 150/99. I blame it on taking the stairs and drinking 3 cups of coffee. The nurse tells me to relax. Five minutes later it was 148/92.
Reading material?

I like to read the pamphlets and health magazines while waiting. Hoping to find something relevant to my personal health, I find only 5 options, 3 of which are in Spanish.
Dr. Malone asks me why I’m here and about my personal and family medical history. I discuss my sleeping problems, and tell him my family physician was considering starting me on a medication for high blood pressure. We discuss sleep hygiene, sodium in my diet, and treatment options for both issues.
Shared decision-making, future steps

Dr. Malone suggests re-starting my sleeping medication and possibly increasing it in the future. He says I don’t need to start an anti-hypertensive medication yet, so we discuss how I might change my diet.
Goals, changes and more homework...

The blood pressure visit summary sheet provides a good overview of our visit and what I need to do at home...

1. Decrease sodium intake

2. Re-start Trazodone

3. Check BP three times in the next week
Pharmacy cold shoulder

After waiting about 15 minutes, I sit down to a seemingly half-interested counselor. I told her I’d be getting my medicine here soon and wanted to start the paperwork. She said she wouldn’t give it to me until I had a prescription... so much for being proactive.
45 minutes later...

Overall, my visit was an excellent experience. The process was relatively easy, the health care provider communicated clearly and included me in the decision-making process, and the staff were friendly.
Number of Steps?

3
- Call to make the appointment
- Fill-out necessary paperwork
- Take my blood pressure twice before the visit (pharmacy and blood drive)

4
- Prepare for appointment: get papers, medicine, directions
- Drive from Raleigh to Chapel Hill, find the clinic
- Follow the signs to the General Internal Medicine Clinic
- Check-in at front desk

5
- Nurse takes my weight, blood pressure
- Review medical history and reason for visit with provider
- Agree on treatment plan and verify understanding
- Check-out at front desk
- Attempt to speak with pharmacy benefits counselor

3
- Re-fill prescription at the pharmacy medicine and check BP
- Have friend check BP, send BP values to Dr. Malone
- Examine food labels for sodium content, attempt to change diet

= 15!
Notable Points

<table>
<thead>
<tr>
<th>Needs Improvement</th>
<th>Done Well</th>
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<tbody>
<tr>
<td>• Specify directions on the Enhanced Care phone system</td>
<td>• Multiple appointment reminders and directions</td>
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<tr>
<td>• Make forms and pamphlets easy-to-read (language and design)</td>
<td>• Friendliness of staff (most)</td>
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<tr>
<td>• Sensitivity toward uninsured</td>
<td>• Short wait time to schedule and see provider</td>
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<tr>
<td>• More pamphlets/health information in rooms</td>
<td>• Provider communication, visit summary forms</td>
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<tr>
<td>• More signs in Spanish</td>
<td>• Signage in English was clear and helpful</td>
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Established Enhanced Care Patient

Followed for over 7 years at UNC, Mr. Holt is more than familiar with the appointment process. He arrives 30 minutes early for his 9:00 a.m. appointment and is happily greeted by two front desk staff that know him by name. In less than 5 minutes, he is called back to see Dr. Malone.
How did you feel when you were first diagnosed with diabetes?

Did the medical providers clearly explain what diabetes is and how to take care of it?

“I had been on about 8 different pills a day. Sometimes, you just forget it.”

“It frightened me – I was scared to death. I had 4 doctors. It was overwhelming.”

“It was easy to understand. They told me what to eat, what not to eat, and they explained my medicine to me.”
Blood pressure check

Mr. Holt is here for a regularly scheduled diabetes and blood pressure follow-up. Dr. Malone intends to simplify his medication regimen so he can take all of his pills once a day.
Mr. Holt takes 5 medicines a day – he takes them out one by one, explaining what they are for, how many he takes and how much they cost

- Metformin B.I.D.
- Enalapril/HCTZ B.I.D.
- Lantus Q.D.
- Baby Aspirin Q.D.
- Simvastatin Q.D.

He checks his blood sugar at least once a day, often before work at 5 a.m.

**Medication review**

Mr. Holt takes two medications twice a day, and admits that he sometimes forgets the second dose.
Review of Warning Labels

“Take it when you eat food.”

“It looks like a glass... I don’t know what it means.”

“It looks like they are showing you how to run your water.”
“If I go out of town, I take what I need. I put the pills in aluminum foil, and I keep my insulin on ice.”

“Sometimes if I miss one, I’ll take 2 later.”

“I’ve used a pill box before.”

“I set my bag of medicine at the table where I eat. I have to keep it where I see it.”

How do you remember to take all of these medicines?
Review meds, create a plan

Dr. Malone reviewed each of Mr. Holt’s medications and interrogated his glucometer. He made sure Mr. Holt was up-to-date on lab work and discussed options to simplify his medication regimen.
Dr. Malone says, “Tell me what you are going to do.” Mr. Holt repeats each of the changes one by one, and Dr. Malone clarifies the directions if needed. At the end of the visit Dr. Malone asks, “Are we good? Any other questions I need to answer?”

**Teach-back**

1. Check BS before breakfast and dinner
2. Increase insulin to 19 units
3. Start Metformin ER 500mg, 4 pills in the morning
4. Start Lisinopril/HCTZ 20/25mg, 1 pill in the morning
5. Stop Metformin and Enalapril/HCTZ

*Used with permission*
Adherence Reinforcement

1. Visit summary sheet

2. Threw away discontinued medications to avoid confusion

3. Patient can now get all medicines at one pharmacy

4. Prescriptions faxed in and ready for pick-up in the afternoon

5. Requested follow-up to review changes and BS

*Used with permission*
Health Literacy Best Practices

- Appointment Reminders
- Kind, Supportive Staff
- Phone Follow-Up
- Confirm Understanding (Teach-Back Method)
- Treatment Simplification
- Shared Decision-Making
- Medication Review (Brown Bag)
Patient Advice

If you had any advice to people that work in the clinic to make information they give you easier to understand, what would you tell them to do?

“I would tell them that they need to write it – not in cursive, in print, and to use small words so I can read it. You see, I can hardly understand those real big words. You have to break down the syllables to understand the big words.”

*Used with permission*
Patient Advice

What about the way they talk to you? Do they explain things in a respectful way? Do they look at you when speaking with you? Do they explain things clearly?

“They explain it very well. They all know me! I come in and say good morning to everyone and they say hello. Everybody is fantastic out there. The nurses are fantastic, too. Since I’ve been coming here I really enjoy myself with the doctors and nurses and staff. They look out for me, so if I make a mistake it will be mine, not theirs, because they really explain things to me.”
Acknowledgements

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