Understanding Health Literacy Skills in Patients With Cardiovascular Disease and Diabetes
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Understanding Health Literacy Skills in Patients with Cardiovascular Disease and Diabetes

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Health literacy is the ability to understand and act on health information and is linked to health outcomes. It is unclear how health literacy skills are developed in patients with complex conditions, such as cardiovascular disease and diabetes. The purpose of this grounded theory study was to gain perspectives of both patients and healthcare professionals on how health literacy skills were developed in patients with cardiovascular disease or diabetes. The research questions addressed how knowledge and skills were acquired, the role of digital tools, instructional strategies used by healthcare professionals, and how the instructional strategies of the healthcare professionals matched the learning preferences and needs of the patients. A social ecological framework was used, which underscored the importance of understanding health literacy from multiple sources. Semistructured
What is health literacy?

Health literacy includes:

- Knowledge
- Communication
- Numeracy
- Navigation
- Decision making
- Education
- Health apps
- Social networking
- Healthcare professionals
- Digital tools & technology
- Connected health devices
- Trusted sources
- Chronic conditions
- Apps
- Connected health devices
- Personalized, interactive, social, & relevant

Specific areas:

- Diabetes
- Blood pressure
- Heart failure
- Heart disease
- Cholesterol
- Wearables
- Internet searches
- Video
- Audio
- Print
- Knowledge
- Connected health devices
- Digital tools & technology
Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Ratzan and Parker).
Health literacy is a public health priority (Nielsen-Bohlman, Panzer, & Kindig, 2004)

90 million Americans have below basic health literacy skills (Kutner, Greenberg, Jin, & Paulsen, 2006)

Low health literacy is linked to poorer health outcomes (Berkman et al., 2011)

HHS developed a National Action Plan to improve health literacy (2010)
My Journey in Health Literacy:

- 30+ years as a clinical exercise physiologist working primarily in a cardiac rehabilitation setting;
- Inpatient and outpatient
- One on one, small groups
- Community and corporate educational sessions

- Degree in Education

- Stories
Story 1:
Can’t use “big” words like “cholesterol”, “carbohydrates”, or “saturated fats” because it makes the reading level too high

If we used that approach with our kids, instead of teaching them to read, we would live in a world in which reading was not necessary
Patient education

Definitions:

Educator: (1) one skilled in teaching; (2) a student of the theory and practice of education *(Merriam-Webster Dictionary)*

Who is that?

- Doctors
- Nurses
- Other healthcare professionals
- Health educators and coaches

*Only 1 of 19 healthcare professionals met the definition*
Health literacy and health outcomes pathway

**Demographic factors:** Race, education, age

**Cultural factors:** Occupation, employment, income, social support, language

**Physical factors:** Vision, hearing, verbal ability, memory, reasoning

**Access and utilization of health care**

**Patient/provider interaction**

**Self-care**

**Health outcomes**

Paasche-Orlow & Wolf, 2007
Health Literacy Research

Focus on low literacy

In most cases, health literacy was a dichotomous, independent variable, with a biometric or health outcome as the dependent variable.

- Heart disease
- Heart failure
- High blood pressure
- Lipoprotein disorders
- Diabetes

Very little research on the impact of building health literacy skills.
The Challenge

Heart disease and diabetes are complex conditions that require a high level of patient involvement

Interpreting lifestyle instructions
Physical activity and nutrition guidelines

Understanding the condition
Names and implications of conditions, diagnostic tests, and treatments

Instructions from the healthcare provider
Medications, symptoms, and follow up

Including the use of large words and concepts, such as cholesterol, saturated fat, carbohydrates, insulin resistance, and angina pectoris
Progression of health literacy skills in chronic diseases

- Reading and comprehension
  - Understanding instructions

- Numeracy
  - Manipulating numbers

- Navigation
  - Understanding how to access healthcare services

- Communication
  - With healthcare providers and caregivers

- Decision making
  - Identifying options, validating the information, and making an informed decision
Where do people get their health information?
Resources:

National Action Plan to Improve Health Literacy
Health Literacy Toolkit

Strategies:
• Plain language
• Teach-back
Role of Qualitative research in the medical literature
TQR 7th Annual Conference Presentations

1. Use of Grounded Theory in Medical Research By Patrick Dunn
3. Qualitative Inquiry in a Distance-based Environment: Thoughts and Tips By Yulia Watters, Darren Adamson, and Deborah Bell
4. Student Veterans’ Experiences in Negotiating Student Services in Higher Education: A Phenomenological Inquiry By Christina Alexander
6. Hearing Minority Parent Voice: Education for All By Barbara R. Wilson
7. The Science Fiction of Qualitative Inquiries By Johnny Salafia
8. New Windows on Patient Experience in Health Care: Blogs, Vlogs, Facebook, and more By Rikid Mangrum
9. Reflections of Choice: Turning to the Arts to Foster Preservice Teachers’ Reflexive Dispositions about Literacy By Janet C. Richards, Sheryl Ashford, Elaine Cerrato Fisher, and Christiana Succar
11. Contemplative Qualitative Inquiry: Zen Principles for the Qualitative Researcher By Valerie J. Jonesick
12. Occupational Health Stress in the Service Sector By Foula Malik and Shaan Shahabuddin
13. Sampling In Qualitative Research: Insights from an Overview of the Methods Literature By Stephen Gentles
15. A Holistic Approach to Reducing the High Rate of Recidivism for Ex-Offenders By Cheryl White
16. Introducing Qualitative Analysis Software with Quirkos By Daniel Turner
17. Outlines for Directed Qualitative Research By Daniel Turner
Grounded Theory

- Interviews
  - Patients → Analytic memos → Theoretical Sampling → Data
  - Professionals
- Theoretical Sampling → Constant comparison → Theoretical saturation → Theoretical explanation
- Constant comparison
  - Deduction
    - Validation
    - Inductive elaboration
  - Open
    - Coding
      - Selective
    - Axial
Clinical sources

- Primary care
- Cardiology

Online sources

- Patient Centered Programs
- Social networking

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**Theoretical Sampling**

- Diagnosed with cardiovascular disease or diabetes?
  - Within past year?
    - Yes
      - Heart disease
      - Heart failure
      - Hypertension
      - Lipid disorder
      - Diabetes

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<th>Sources</th>
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<td>Medical group</td>
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<td>6</td>
<td>Patient focused programs</td>
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<tr>
<td>Female</td>
<td>10</td>
<td>Social media</td>
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<tr>
<td>Average age</td>
<td>55.4</td>
<td></td>
<td></td>
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<tr>
<td>Under age 40</td>
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<td>Heart attack</td>
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<td>40-65</td>
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<td>Over 65</td>
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<td>High blood pressure</td>
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<td>High school graduate</td>
<td>9</td>
<td>Dyslipidemia</td>
<td>4</td>
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<td>College graduate</td>
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<td>Diabetes</td>
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<tr>
<td>Master’s degree</td>
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<td>Congenital heart defect</td>
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<td></td>
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<td>Care giver</td>
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<tr>
<td></td>
<td></td>
<td>Irregular heart beat</td>
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## Healthcare professionals

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<th>Professional type</th>
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<td>Male</td>
<td>5</td>
<td>Nurse</td>
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</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>Nurse practitioner</td>
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<tr>
<td>Average age</td>
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<td>Under 40</td>
<td>4</td>
<td>Pharmacist</td>
<td>1</td>
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<tr>
<td>40-65</td>
<td>13</td>
<td>Dietitian</td>
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<tr>
<td>Over 65</td>
<td>2</td>
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<td>Average years of experience</td>
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<td>Medical Assistant</td>
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<td></td>
<td></td>
<td>Health educator/coach/designer</td>
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<td>Resources and technology</td>
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<td>Programs and interventions</td>
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<td>Teaching methods</td>
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<td>Emotions</td>
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<td>Process</td>
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<td>36</td>
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**Research question 1:** What are the perspectives of patients and healthcare professionals in the development of health literacy skills in patients that have been recently diagnosed with a coronary artery disease, heart failure, hypertension, a lipoprotein disorder, or diabetes?

**Key Theme:** *Social support is a learning opportunity*

<table>
<thead>
<tr>
<th>Categories</th>
<th>Selected extract</th>
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<tbody>
<tr>
<td>Emotional support</td>
<td>The support groups help me to learn. The buddy forms and patient forms, you get to talk to other people. When you hear the same thing from multiple forms, it helps you to start to make sense. I learned about studies that had been done, and the results. I would never have known without being connected to those groups. You find out little details that might not be important to the doctor, but helps to explain things. <em>P12.</em></td>
</tr>
<tr>
<td></td>
<td>So I think there is some kind of personal connection, and reassurance that there are other people out there going through a similar experience. <em>HP5</em></td>
</tr>
<tr>
<td>Behavioral</td>
<td>A lot of the behavior I observed is expected, and made sense to me. At the same time, I have been impressed by it, because you read so many things that people are just lazy and they don’t care about their health, but it was absolutely not the case. It was an older population, every one of them was over 55, and they were all well informed, it seemed like. <em>HP7.</em></td>
</tr>
<tr>
<td></td>
<td>Understanding what they actually did. I did not really know medically what was going on, so that I was more aware of my choices. I felt at the time like everything was bleak, because I did not know the choices. <em>P2</em></td>
</tr>
<tr>
<td>Programs</td>
<td>Cardiac rehab had the biggest impact because emotionally, I was a mess, a mess, I mean just don’t know how people do it, I didn’t even conceptualize that, you know, I didn’t die, but I wasn’t, I had a lot of fear. <em>P1</em></td>
</tr>
<tr>
<td></td>
<td>He directed me to the Game of Health. He was able to keep track us and a lot better. It was the camaraderie of the group, people that were losing and not losing and I learned things I forgot I knew. I was depressed myself. Because I would gain weight, I would chastise myself. <em>P4</em></td>
</tr>
</tbody>
</table>
How does the support system impact health literacy?

- Social & Emotional support
- Reduced anxiety
- Sharing experiences
- Instructional platform
- Health literacy skills
### Research question 2: What are the perspectives of patients and healthcare professionals in the use of new technologies to build health literacy skills?

#### Key Theme: Google is a health system

<table>
<thead>
<tr>
<th>Categories</th>
<th>Selected extract</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self directed/ personal experience</strong></td>
<td>I get most of my information from the internet. I have been misdiagnosed, so I do a lot of my own research. P16.</td>
</tr>
<tr>
<td></td>
<td>A lot of them turned to journals and really reliable resources, such as the Mayo Clinic, or medical journals. So they were reading what I would consider very high level stuff. The selection of these sources was based on the credibility of the source, and the visibility of the source. So people know about the Mayo Clinic, they know about Harvard Medical. The other place they got information from was friends and family. Some of them would have medical professionals in the family they would turn to, and since they trusted the person, they trusted the information they gave. HP7</td>
</tr>
<tr>
<td><strong>Role of tools</strong></td>
<td>I see such as natural fit, in my experience, when someone was diagnosed they would turn to digital tools for more information. On a day to day routine, where we all engaged digitally, throughout the day, that seemed to be a comfortable form of information, for many age demographics, not all. I would say the need for validated instruments, for trustworthy resources, that was always huge. It was not a google search, but a warehouse of vetted, and validated knowledge, similar to going to the heart.org website. Knowing that you have a stamp of approval and thorough science review really does give people comfort as they are taking in all of this information. HP2</td>
</tr>
<tr>
<td></td>
<td>I use google and put in key words until I find what I am looking for. I kind of already know, from my family history what I am looking for and what I need to do. P6</td>
</tr>
<tr>
<td><strong>New tech confusion/digital divide</strong></td>
<td>I was using a Fitbit until I killed it. P4</td>
</tr>
<tr>
<td></td>
<td>I don't even have a cell phone. P2</td>
</tr>
</tbody>
</table>
Research question 3: How do healthcare professionals and health educators assess and build health literacy skills in their patients?

Key theme: Instructional strategies should be personalized, interactive, social, and relevant.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Selected extract</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traits</td>
<td>So it has to be <strong>personalized</strong> and <strong>individualized</strong>, so that it is <strong>relevant</strong> to their lives. I think you have to go to where the person is, and meet them there and find out what works for them, but I think it is going to be more <strong>specific</strong> and <strong>customized</strong>. <em>HP1</em></td>
</tr>
<tr>
<td>Integration</td>
<td>Do I try to give patients very practical examples? I tell them stories, patients remember stories. And it sticks with them. And I give them <strong>examples of other patients that were successful</strong>, and kind of how they thought through things so they can see, ok this is the process. It tells them, it is time to learn. It is so overwhelming. <strong>I assess where they are emotionally</strong>. If they are overwhelmed, we can’t get complicated at all. We need to go over the basics. <em>HP3</em></td>
</tr>
<tr>
<td>Format</td>
<td>The information I received from my doctor was good, but I was curious to learn more. The print material was helpful, but too general. <em>P8</em></td>
</tr>
</tbody>
</table>
**Research question 4:** How are instructional strategies designed to build knowledge and health literacy used by healthcare professionals? aligned with the process of learning described by the patients?

**Key theme:** Patients are self-directed learners

<table>
<thead>
<tr>
<th>Categories</th>
<th>Selected extract</th>
</tr>
</thead>
<tbody>
<tr>
<td>No patient left behind</td>
<td>It depends on the condition, but <em>if they are not making changes and are not motivated he does not like to keep them as a patient</em>. We will have them find another doctor. <em>HP9</em></td>
</tr>
<tr>
<td>Healthy distrust</td>
<td><em>...question their doctor very closely.</em> If they don’t have a sympathetic ear, leave it, because you need all the support you can get.* <em>P2</em></td>
</tr>
</tbody>
</table>
Axial Coding

**Causal Conditions**
- Heart disease
- Heart failure
- Hypertension
- Dyslipidemia
- Diabetes

**Phenomena**
- Development of knowledge and skills

**Intervening Conditions**
- Emotional state
  - Stages of loss
- Influencers
- Behavioral approach
  - Readiness for change
  - Hierarchy of needs

**Context**
- Support system
- Access to resources and technology
- Format

**Strategies**
- Support system
- Programs and interventions
- Traits
  - Personalized
  - Relevant
  - Interactive

**Consequences**
- Healthy distrust
- Self-directed
- Personal experience
- Tech confusion
- Digital divide
- Confidence
- Reduced anxiety

**Format**
- Strategies
- Support system
- Programs and interventions
- Traits
  - Personalized
  - Relevant
  - Interactive

**Context**
- Support system
- Access to resources and technology
- Format

**Strategies**
- Support system
- Programs and interventions
- Traits
  - Personalized
  - Relevant
  - Interactive

**Consequences**
- Healthy distrust
- Self-directed
- Personal experience
- Tech confusion
- Digital divide
- Confidence
- Reduced anxiety

**Format**
- Strategies
- Support system
- Programs and interventions
- Traits
  - Personalized
  - Relevant
  - Interactive
Theoretical explanation: Health literacy instructional model

1. New Diagnosis
2. Emotional support
   - Good
   - Behavioral approach
   - Yes
   - Instructional Strategy
3. Not Good
   - No
   - Find social support system

Address emotional state
Provide social and emotional support
Implications?

What is needed?

- Better understanding of the relationship between social and emotional support and health literacy
- Development of more effective tools and programs
- Development of more effective strategies for healthcare professionals
- Need for better options for unmotivated, non-self-directed learners – leaving no patient behind.
Thank you! Questions?