

Health Literacy in Context: Patients Perceptions about what Health Literacy Skills they Perceive as Important when Navigating through the Healthcare System, and in Managing their Health

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Study's Importance and Context

- Health Literacy is studied with an epistemic objectivity—that is health literacy is defined as a set of an individual's skills that can be quantified and measured (Rubinelli, Schulz, & Nakamoto, 2009)
- Very few studies explored health literacy from patients' perspective
- Also very few studies have analysed HL as an outcome of interaction between the healthcare system and an individual's HL skills
- We fill this gap in research by exploring health literacy skills from chronic patients' perspective

Context

- Chronic patients were chosen for their proclivity to use health information more regularly
- Chronic patients' experiences with the health ailments is complex
- Provides a rich context to study health literacy and health communication practices and perspectives

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Study's Context | Research Methods

- Study was conducted in Singapore, a small city state in Asia
- One of the best health care systems in the world
- Subjects were chronically ill diabetic and heart stroke patients
- Study used qualitative methods-12 focus group discussion
- Approximately 60 participants (44 patients and 26 caregivers) took part in the study
- Caregivers were included as they played a key role in helping older patients to manage their health
- 2 focus group discussions were conducted in Mandarin, which were translated into English by one of the authors, who was well versed in both the languages
- Discussions were transcribed, and data was analysed using Grounded Theory methodologies (Charmaz, 2000)
- 5 key themes emerged in the study

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Theme-1: "Understanding their Health Condition and the need to know when and what preventive steps to take"

- "Patients tend to be more reactive than proactive around chronic conditions"
- "Family histories", "signs" "symptoms" and "indicators" are often ignored
- "no explicit symptoms does not mean that you are not at risk"
- "if you have family history, it is important to be proactive and act early"
- "Recognizing the importance of early prevention and preventive steps"

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Theme-2: Broad Nature of Health Information: Establishing Credibility and Relevancy of Health Information

- "Information that is publicly available, is very general, what we need is information that is applicable to our context"
- "Chronic patients experience the same disease differently, one size fits all does not apply here"
- "We must learn how to interpret the information that we get and know if its applicable in our context"
- "We must know how to apply this information to solve our health problems"

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Theme-3: Asking the Right Questions and Being Active Communicators in Doctor-Patient Encounters

- "Patient-doctor encounters were a primary focus for chronic disease patients to obtain and verify health information"
- "This is about me, my health, and so I am primarily responsible for it"
- "To obtain right answers, we must know how to ask all the relevant questions"
- "We must not hesitate to ask questions"
- "We need to be assertive, and tell the doctor what we want, and what we don't want"
- "it is not necessary that the Doctor is always right"
- "I often take information I got on he Internet and ask if him (sic) (doctor) if this applies to me"
- "I ask why this, why not this"

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Theme-4: Finding and Understanding the Invisible Connections between Disparate Bits of Health Information and Understanding How this Can Affect their Health

Chris, a diabetic patient with heart problems described an incident about his uncle's death brought about, in part by the inability to make the "invisible connections:

"I remember, when my uncle passed away because of cardiac arrest [...], I asked the doctor [...], how come he [uncle] did not complain of chest pain if he had a heart attack? How come he did not know he was having a heart attack? In response the doctor said, oh this is because you know he was diabetic and he took this diabetes medicine, this probably numbed his nerves, so he will not feel anything if he has a heart attack."

Such incidents underscore how comprehending health information is a rather complex cognitive activity and the importance of finding these invisible connections that affect patients health.

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Theme-5: Using Health Information to Resolve Health Issues

"Merely getting information does not help, we need to ensure that we use this information"

"Managing timelines /dosage regimens"

Strategies-

1. "Color coding to ensure that I take the right tablets at right time"
2. "Setting reminders"

Challenges:

1. Noticing any changes in current health status
2. Managing any side effects due to co-morbidities"
3. Emotional state and cognitive capacity
4. Capacity to comprehend instructions in older patients
5. Language and communication barriers

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Theme-6: Structural Factors that Influence Patient's Health Literacy Skills

- Time-pressured clinical patient-provider interactions that hindered verbal communication
- Computerization and de-humanization of patient-provider interaction
- Making healthcare choices and complexity associated with insurance paperwork
- Hidden costs when making healthcare choices –e.g. procedures

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Implications for Healthcare

- Findings highlight some of the challenges in context to patient-doctor interactions and can inform better strategies for improving this communication
- Findings are useful for improving educational programs aimed at chronically ill patients and patients in general
- Underscores the importance of qualitative methods in health education research to complement much of the research that is conducted from an "epistemic objectivity"

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Compliments and Contact Information

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Thank you

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