Rehabilitation Narratives: Considering the Patient Experience

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What is narrative medicine?
- Storytelling: an innate human impulse, way we make sense of ourselves, relationships, and environments
- Listening to patient narratives gives voice to the suffering of illness and allows providers to tap into their innate humanness
- Ways we listen are diverse, feeling of being listened to is universal

What does it mean to take a narrative approach to patient care?
- Display narrative humility: listener is a neophyte in patient’s story
- Each story is new opportunity and a privilege in patient’s experience of illness
- Cannot fully understand another person’s experience, yet willingness to try is essential

Growing body of evidence across fields

How narratives can change nursing practice

Power and Promise of Narrative for Advancing Physical Therapist Education and Practice
Tell Me Your Story: Pilot Narrative Medicine Curriculum

- Qualitative study: Third-year medical students on internal medicine rotation elicited patient stories, read back stories to patients, and wrote reflectively.
- Patient responses:
  - Students interpreted their stories correctly: "...he was painting and being, like, 'yes...that's totally what it feels like right now.'"

Student responses:
- Patients are more than their disease
- Be open to opportunities to slow down and listen
- Stories give new insights into patients
- Stories can affect patient care
- Patients as individuals

Why might this approach be beneficial to providers?

"Patient stories add physical essence to intangible concepts like pain, compassion, anguish, or collaboration. Stories put faces on statistics and patient experience scores, and they remind health care workers why they became caretakers in the first place."

What is particular about rehabilitation?

- Diversity of diagnoses: acute, traumatic to chronic, progressive
- Psychological adjustment to new capabilities and limitations to explore complexity of:
  - function
  - ability
  - independence
  - meaning and purpose
  - quality of life
- Narrative medicine provides approaches to explore these rich narratives

Personal Narratives of Rehabilitation purpose: to explore personal narratives of rehabilitation

Methods

Because this project did not meet the federal definition of research, it did not require IRB review/approval.

1. Adults receiving inpatient rehabilitation (stroke, spinal cord injury, and general) were screened for communication ability, psychosocial stability, and intact cognition
2. Patients were approached by the medical student interviewer
3. Participating patients signed a photography and audio release prior to interview
4. Semi-structured interview included psychological adjustment to physical changes, importance of support, and future functional goals
5. Audio recordings were coded for content, and themes were developed

Semi-structured interview questions

Tell me the story about how you came to the UPMC Rehabilitation Institute.
What are your goals during your time here?
How have you seen yourself change during your time in inpatient care?
What aspects of rehabilitation do you find most challenging?
Tell me about the role of family, friends, co-workers, etc. have in your care.
What types of support (e.g. instrumental, social, or emotional) are most important to you?

Semi-structured interview questions

How have you been adjusting to your abilities and limitations?
Do you have any concerns that you might not be able to do all the things we are asking to do?
Do you have any concerns that you might not be able to live the life you want?
What are your goals after you leave inpatient care?
How do you envision your future?
Results

- N=12
- Interview length: 16-46m (μ = 28m)
- Mostly female (n=10, 83%)
- Age: 20s-80s
- Sample diagnoses:
  - Multiple sclerosis
  - Tendoscopy
  - Back surgeries
  - Stroke
  - Cerebral palsy
  - Septicaemia

Common reported themes:

- Importance of positive thinking, gratitude, and hope
- Achieving independence regardless of ability
- Camaraderie among patients
- Frustration in limitations
- Experience of a new normal
- Lack of novelty in provider experience of patient injury

“Basically, there are two ways to deal with things: you can curl up in a corner, suck your thumb, and cry and pity yourself. Or you can say, you know what, I’m going to work as hard as I can, see what happens, and go from there. And that’s the one I choose.”
Common reported themes:
- experience of new normal

“I used to be pretty independent, used to jump in the car, and go wherever I want to go. I can’t do that anymore. So, I’ve reached a new reality. It’s weird whenever you wake up, and yesterday is gone.”

Common reported themes:
- lack of novelty in provider experience of patient injury

“The doctors, I mean, they treat it, and they see it, but they don’t quite understand how difficult things really are. How hard like, my life went from being easy to really hard. I don’t have a single day when things are just easy. It’s like nothing is easy.”

Common reported themes:
- acceptance of different capabilities and limitations or lack thereof
- staying determined to push oneself
- worry about the ability to regain function and possible health decline
- vigilance in maintaining health
- role of faith in recovery

Common reported themes:
- acceptance of different capabilities and limitations or lack thereof

“Well if I accept my situation, it’s me right there, I’m giving up. And that’s the way I look at it. I’m going to fight, I’m going to work, I’m going to train.”
Common reported themes:
- worry about the ability to regain function and possible health decline

“It’s kind of scary not knowing what’s going to happen down the road. Am I going to get everything back? And they can’t tell me, ‘Yeah, you are,’ because they don’t know.”

Common reported themes:
- vigilance in maintaining health

“Now, I know life has serious consequences. I never put much thought into my health. You know, I was having health problems before this, I just never put much thought into it. Now, I know that I have to be more proactive on my own health. And if I think something is wrong, and I think what they’re doing is not right, I have to be like, ‘Hey, this isn’t right. Something is definitely wrong.’”

Common reported themes:
- role of faith in recovery

“I look at this, this is what God has given me. So, I have to accept it and go on. I mean, nothing is going to change. It is only going to progress. So, I have to deal with it, make the best of it. It’s going to hurt no matter what. So, do what you can, and be thankful for what you have.”

Effect on Interviewer:
- Deeper understanding of the patient experience
- Importance of a holistic approach to providing better medical care
- Protective strategy against burnout
Conclusion: embrace patient perspective

References


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