Empathy and Compassion in Rehabilitation

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Objectives

• Learn the defining features of clinical empathy
• Learn about the impact of empathy on clinical outcomes
• Consider how empathy and emotion impact rehabilitation care
Research and clinical interests

• Meaning-making in emotional situations - for the patient, family member and Health Care provider
• The reverberating effects of illness and injury
• The impact of “tough cases” and dilemmas on Health care providers
Defining Empathy
Empathy
What is empathy

What Is Empathy?

The term “empathy” is used to describe a wide range of experiences. Emotion researchers generally define empathy as the ability to sense other people’s emotions, coupled with the ability to imagine what someone else might be thinking or feeling.

Contemporary researchers often differentiate between two types of empathy: “Affective empathy” refers to the sensations and feelings we get in response to others’ emotions; this can include mirroring what that person is feeling, or just feeling stressed when we detect another’s fear or anxiety. “Cognitive empathy,” sometimes called “perspective taking,” refers to our ability to identify and understand other peoples’ emotions. Studies suggest that the two types of empathy are not always in sync, with affective empathy reactions tending to overlap with physiological responses, while cognitive empathy reactions may be moderated by individual differences and cultural norms.
What does it mean to be empathetic?

Psychological and Philosophical definitions

- Affective
- Cognitive
- Relational

What does it mean to be empathetic?

• Empirical research on empathy
  • Quantitative and qualitative
  • Typically Self-report
  • No general agreement on how to define, teach or study empathy\(^{(1)}\)
• Multidimensional
• Key component of gaining trust and establishing rapport

Empathy

• Empathy vs. Sympathy

• “... empathy pushes one to appreciate that another see things differently, whereas sympathy may blur such differences.” (pg 697)

Clinical empathy

• “A complex affective-cognitive activity involving emotional attunement and imagining how another person feels”

• “Engaged curiosity about another person’s perspective”

• “Tell me what I am missing”

Empathy vs. detached concern

• “The irony of detachment is that in seeking “objective reality,” physicians ignore an important source of understanding reality. Through empathy, physicians allow patients’ suffering and emotional needs to be real…. By allowing patients to move them emotionally, physicians enable more than the physical repair of bodies; they allow the healing to begin.” (pg 145)
Empathy and Curiosity

• “Curiosity is ongoing attentiveness and openness to what patients communicate, verbally and nonverbally.” (pg 131)

• Without ongoing curiosity, a physician can make the mistake of thinking that the intensity of her own affective experience corresponds to the depth of her understanding of a patient.” (pg 132)
How do you communicate empathy?
Communicating Empathy

• Nonverbal
  • Facial
  • Gestural
  • Tonal

• Verbal
“Empathy Bingo”

https://positivepsychologyprogram.com/kindness-activities-empathy-worksheets/#empathy
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Examples

• A: I’m worried about having enough money to pay my bills this month
• B: I’ll loan you the money

• A: Look at my scar from the cycling accident
• B: That’s nothing, you should see the one on my knee

• A: I got caught in traffic for 2 hours in 100 degree weather with no air conditioning
• B: That reminds me of the time.....
Examples

- A: It’s scary for me to get up and speak in front of people
- B: I think you should join toast masters

- A: I lost my job
- B: Cheer up, let’s go eat

- A: I have so much to do today
- B: Are you feeling overwhelmed and want support?
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Brene Brown on Empathy
RSA shorts www.theRSA.org)
https://www.youtube.com/watch?v=1Evwgu369Jw

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Brene Brown

• “Empathy fuels connection”

1. Perspective taking
2. Staying out of Judgment
3. Recognizing emotion in other people
4. Communicating emotion
Brene Brown

• “Empathy is a vulnerable choice”

• “We try to ‘put the silver lining’ on it”

• “The truth is, rarely can a response make something better. What makes something better is connection.”
Research on Empathy
Measures

- Interpersonal Reactivity Index
- Toronto Empathy Questionnaire
- Jefferson Empathy Scale
- The Questionnaire of Cognitive and Affective Empathy
Measure: iNTERPERSONAL REACTIVITY INDEX (IRI)

Defines empathy as the “reactions of one individual to the observed experiences of another (Davis, 1983).”

28-items answered on a 5-point Likert scale (1980, 1983)
4 subscales, each made up of 7 different items.
• Perspective Taking
• Fantasy
• Empathic Concern
• Personal Distress

Jefferson Scale of Empathy

Empathy in patient care... “a cognitive attribute that involves an ability to understand the patient’s pain, suffering, and perspective combined with a capability to communicate this understanding and an intention to help.”

Permission to use the Jefferson Scale of Empathy has been given in 74 countries. The JSE has been translated into 55 languages/dialects (PDF). Learn more about the worldwide use of the JSE (PDF).

Center researchers developed The Jefferson Scale of Empathy (JSE) to measure empathy in physicians and other health professionals.

Versions:
Empathy “levels”

Empathy and outcomes

**Acad Med.** 2011 Mar;86(3):359-64..
Physicians' empathy and clinical outcomes for diabetic patients.  
Hojat M, Louis DZ, Markham FW, Wender R, Rabinowitz C, Gonnella JS.

**Acad Med.** 2012 Sep;87(9):1243-9.  
The relationship between physician empathy and disease complications: an empirical study of primary care physicians and their diabetic patients in Parma, Italy. 
Empathy and competence

Patient Educ Couns (2013), http://dx.doi.org/10.1016/j.pec.2013.05.016
Internal Barriers

“And I suppose that’s what physicians do you know, just come in and say you have cancer and walk out and you don’t have to deal with your own emotions. And so it may not be... that they’re not empathetic, they just don’t want to be too vulnerable. You know, because as soon as you open yourself up you start... becoming too involved with patients.” (H. Bayne et al, 2013)
External barriers

• “I think unfortunately what medicine’s turned to nowadays is it’s less about what the patient’s feeling and more about what the insurance company telling me I have to do, what I gotta give, and how I’m getting out of here by such and such hour”
Patient role

• “Yeah, some people aren’t very nice. You know? Some people who come in, they’re kind of endearing... And some people are just horribly mean. And they were mean to start with, and now you put them in a bad situation, and now you put them in a bad situation and they become downright brutal. And there are just some people you don’t want to go and deal with, and just very, very short because you don’t feel like taking their abuse.”
Compassion
Compassion

Related concepts:
• Empathy
• Kindness
• Altruism
• Care
• Pity
Compassion

Five elements
1. Recognizing suffering
2. Understanding the universality of human suffering
3. Feeling for the person suffering
4. Tolerating uncomfortable feelings
5. Motivation to act/acting to alleviate suffering

What is compassion and how can we measure it? A review of definitions and measures.

Compassionate Healthcare

• The Schwartz Center for Compassionate Healthcare

• http://www.theschwartzcenter.org/

• BOSTON (June 27, 2017)—The Schwartz Center for Compassionate Healthcare, a national leader in the movement to strengthen and sustain the human connection at the heart of healthcare, today announced the results from a national poll of patients, physicians and nurses that indicated that while patients feel more positively about the U.S. healthcare system today than in 2010, they’re concerned, as are physicians and nurses about the future of compassion.
Compassion

Definition of compassion

: sympathetic consciousness of others' distress together with a desire to alleviate it

• https://www.merriam-webster.com/dictionary/compassion
Emotion and Cognition
Emotions in Medicine

• “The doctor-patient [clinician-patient] interaction is fundamentally a human connection, and emotions are a de facto part of it” (pg 210)

“In general, empathy is easier the more we can identify with someone. When we can genuinely envision ourselves in a situation, it’s possible to intuit what that person’s suffering might feel like. When the gap between doctor and patient is larger – for whatever reason – the challenge is thornier.” (Ofri, pg 16)
Emotion

• “Emotion: A complex pattern of changes, including physiological arousal, feelings, cognitive processes, and behavioral reactions, made in response to a situation perceived to be personally significant.”

• American Psychological Association Glossary of Terms
Emotion: Plutchik's wheel

Emotions

Atlas of Emotions

• http://atlasofemotions.org/#continents/
Emotional Space – Distance and Connection
Cognitive Biases

• Streamline Information-processing
• Impact human judgement
• Affect decision-making

• “Systematic errors highlight the psychological processes that underlie perception and judgement” (Tversky & Kahneman, 1999)
Confirmation Bias
Confirmation Bias

• Favoring of information that confirms beliefs or hypotheses
• Interpreting ambiguous evidence as supportive of belief

• Attending to information selectively
• Remembering information selectively

• Effect is stronger for deeply held beliefs
• Effect is stronger for emotionally laden topics
Fundamental Attribution Error

- Perceive
- Judge
- Attribute

- We believe our own actions are situational or based on context
- We believe others actions are dispositional or based on personality or character or more stable aspects
Contact Bias

- Healthcare providers interact with patients when they are physically and often emotionally vulnerable.
- The full context of the person’s life is not as obvious as is the list of problems, difficulties and ailments.
- May be impacted by ‘anchoring’ or the use of an initial piece of information to make subsequent judgments.

- This contact bias reifies notions of patienthood.
Asch: Distracted by Disability

Special Section: Difference and the Delivery of Healthcare

Distracted by Disability

ADRIENNE ASCH

The “Difference” of Disability in the Medical Setting

People with disabilities use more medical care and see health professionals more often than do those of the same age, ethnic group, or economic class who do not have impairments. An indisputable medical goal is “preventing, ameliorating, or curing disease and its associated effects of suffering and disability,
“The bioethics and medical literatures have not fully absorbed the reports of people with disabilities or of social researchers indicating that the majority of disabled people consider their lives somewhat or very satisfying.” (Asch, 1998. pg. 79)
Challenges in Rehabilitation
Aspects to consider

• Ableism
• Projection
• Disability Culture
• Diversity
• Inspiration
Ableism

Definition of ABLEISM
• : discrimination or prejudice against individuals with disabilities
• — able·ist adjective
• First Known Use of ABLEISM
• 1981

• http://www.merriam-webster.com/dictionary/ableism
Empathy is not projection

- Golden Rule thinking and Disability

Abandoning the Golden Rule: The Problem with “Putting Ourselves in the Patient’s Place”

Sunil Kothari and Kristi L. Kirschner

A large body of evidence documents the difficulties health care professionals have in predicting their patient’s beliefs or wishes. These difficulties extend from the predictions of very specific patient wishes (such as for life-sustaining therapies) to more global assessments of patients’ lives as a whole (for instance, their quality of life). Although many explanations have been offered for this phenomenon, we discuss one that has not received as much attention: the conscious or unconscious adoption of what we refer to as Golden Rule thinking. This refers to our attempts to understand another person’s situation by imagining what we would believe or want under similar circumstances, in other words, “putting ourselves in the patient’s place.” Although Golden Rule thinking would seem to be a promising strategy, studies show that it actually results in inaccurate predictions of patients’ wishes or beliefs. These mispredictions, in turn, have significant clinical and ethical implications. We review possible reasons why Golden Rule thinking may be of limited utility in understanding our patients’ situations and suggest alternate strategies to maximize our understanding of our patient’s lives. Key words: attitude of health personnel, clinical ethics, decision making, disabled persons, physician–patient relations, quality of life
Clash of Cultures

Medical Decision Making and People with Disabilities: A Clash of Cultures

Paul K. Longmore

In discussions of medical decision making as it applies to people with disabilities, a major obstacle stands in the way: the perceptions and values of disabled people (particularly disability rights advocates and disabled social scientists) and of many nondisabled people (particularly health care professionals, ethicists, and health policy analysts) with disabilities need legal protection against discrimination. This minority group consciousness is also expounded through political activism. The adversarial relationships and conflict of values between medical professionals and persons with disabilities can only be understood in the context of this minority group consciousness.

Background: Disability Studies

• An interdisciplinary field with intellectual roots in the social sciences, humanities & rehabilitation sciences

• The power of explanatory models is great
Medical Model

• Disability is negative or pathological

• Disability resides within the patient

• Solution for disability-related problems is cure

• Expert is the health care professional
Social Model

• Disability is a difference

• Disability resides in the interaction between the person and Society

• Solution is to change the relationship between the person and society

• Expert can be the person, an advocate or anyone who changes the relationship
Diversity

• “Their disabilities varied so widely that that it was difficult – even deceptive – to generalize about such women....” (pg 127)
Disability as Inspiration

• https://www.youtube.com/watch?v=8K9Gg164Bsw
Implications for Ethics
Core Principles of Biomedical Ethics

• Beneficence
• Respect for Autonomy
• Nonmaleficence
• Justice

Ethics

Various theories and frameworks can be used to analyze ethical considerations, including a focus on
• Principles
• Relationships
• Virtues
• Consequences
• Rules
• Process

Care Ethics/Ethics of Care

• Relational
• Dependence and Interdependence
• Contextual features
• Often associated with feminist ethics
  • Theorists include Carol Gilligan, Ned Noddings, Eva Feder Kittay
Substituted judgment

Surrogate decision-makers are instructed to make decisions as he/she believe the patient would if they could.
Substituted Judgment

• Perspective of the Decision-maker
  • Egocentric
  • Simulated
  • Projected
  • Benevolent

Substituted Judgment

• “Three separate but related lines of research show the weaknesses of substituted judgment”

  • Preferences change over time
  • Accuracy of surrogate decisions
  • Patients want input from family and clinicians

(Torke, Alexander & Lantos, 2008)
Best Interests

In the absence of known wishes, a best interests criterion is used; i.e., the decision-maker makes a decision in the best interest of the patient, weighing the benefits and burdens of treatment in light of the patient’s condition.
“Defining the Good Life Following Acquired Physical Disability”

Various Terms

- Life satisfaction – overall belief that one’s life is a good one
- Quality of life – a summary index of expectations, evaluations, emotions and achievements factoring into the good life
- Subjective well being – an overall assessment that one’s life is good coupled with relatively high levels of ongoing positive affect and correspondingly low levels of negative affect
- Happiness – a shorthand for these other constructs which overlap with one another conceptually and empirically
Limited predictive power of many variables

- No or low correlation
  - Income
  - Education
  - Social Class
  - Intelligence
  - Age
  - Gender
  - Physical Attractiveness
  - Race/ethnicity
  - Offspring
  - Climate
Impact on Clinicians
Related Concepts in the literature

• Compassion Fatigue
• Burnout
• Moral Distress
• Vicarious Traumatization
• Secondary Traumatic Stress
Measure: Professional Quality of Life scale

The ProQOL is the most commonly used measure of the negative and positive affects of helping others who experience suffering and trauma. The ProQOL has sub-scales for compassion satisfaction, burnout and compassion fatigue.

http://proqol.org/uploads/ProQOL_5_English.pdf
Measure: Professional Quality of Life scale
Moral Distress

• The stress experienced when there is a conflict between the individual’s values and the situation in which they find themselves

• “Traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the health care provider feels she/he is not able to preserve all interests and values at stake”

Moral Distress in Rehabilitation Professionals: Results From a Hospital Ethics Survey

Debjan Mukherjee, PhD, Rebecca Brashler, Lcsw, Teresa A. Savage, PhD, RN, Kristi L. Kirschner, MD

Objective: Moral distress in the rehabilitation setting was examined in a follow-up survey. The survey had 3 goals: (1) to systematically and anonymously gather data about the ethical issues that employees struggle with in their daily work; (2) to raise the visibility of the hospital-based ethics program and resources available to employees; and (3) to prioritize and focus the direction of the program’s educational seminars, quality improvement projects, and ethics consultation.

Design: Online survey of employees.

Setting: Urban rehabilitation system of care.

Participants: The survey was open to all employees; 207 completed the survey.

Interventions: N/A

Main Outcome Measurements: N/A

Conclusions: Three broad categories of moral distress were identified: institutional ethics, professional practice, and clinical decision-making. Institutional ethics issues related to the health care environment, such as health care reimbursement pressures and corporate culture. Professional practice issues involved codes of behavior and concepts of professionalism, including patient confidentiality/privacy. Clinical decision-making included such practical dilemmas as conflicts around goal-setting, discharge planning, and assessment of decision-making capacity. An anonymous survey of staff members allowed the hospital ethics program to identify sources of moral distress and prioritize strategies to address them.

INTRODUCTION

Stories of resilience and adjustment are the highlight of work in rehabilitation. If these stories unfolded in a vacuum, there would be no need to think about ethical concerns in the environment. However, these stories unfold in a fast-paced, ever-changing world of new technology, complex health care systems, convoluted reimbursement criteria, and enormous financial pressures. Patients bring unique personalities, values, and life histories to their rehabilitation, along with family members who have their own needs and perspectives. They return to communities that do not yet embrace those with impairments and sometimes even perpetuate unduly negative views of people with cognitive and physical disabilities [1,2].
Clinical Decision-making: Goal-setting

“A patient had significant swallowing problems and was unable to eat. Despite continuous family education they continued to give him food and would become upset when he would choke.”

“A seeming attempt to discourage hope in the name of realistic acceptance of disability. Acute rehab is too early to have a definitive answer to long-term outcomes.”
Compassion Fatigue

feeling overwhelmed by a patients suffering and caring for patients until the professional is “drained of empathy”

“Compassion fatigue may be emotionally devastating for caregivers particularly since incidents that trigger the phenomenon are unavoidable and most individuals have difficulty recognizing their own compassion fatigue”

Burnout and Vicarious Traumatization

• “Vicarious trauma is the emotional residue of exposure that counselors have from working with people as they are hearing their trauma stories and become witnesses to the pain, fear and terror that trauma survivors have endured.”

• American Counseling Association
What strategies do you use to stay engaged, empathetic and compassionate?
Interventions

• Mindfulness
• Self-compassion
• Self-care
• Social connectedness
• Diversifying coping strategies
• Narrative Medicine
Mindfulness

“Mindfulness means paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally”

Mindfulness

• “In our habits we become automatons – at times, unaware, unfeeling, and distracted. These habits lead to the loss of presence, the loss of awareness, and the development of routine interaction and interpersonal responses.”

Mindfulness

• “By developing such awareness, physicians can experience a sense of the transformation of the sense of self. Feelings of spaciousness, including ease, patience, trust, and compassion, may arise. This personal space may enable true caring for the patient, or the capacity to “be with” the patient’s situation, or even patience – the enduring of pain or trouble with calmness and composure.” (p. 87)

Self-compassion

“...Self-compassion involves treating yourself with care and concern when considering personal inadequacies, mistakes, failures, and painful life situations.”

Self-Compassion

“It comprises three interacting components:
• Self-kindness versus self-judgment
• Sense of common humanity versus isolation
• Mindfulness versus over-identification”

Summary

• Empathy
• Compassion
• Emotion & Cognition
• Challenges in Rehabilitation
• Implications for Ethics
• Impact on Clinicians