



Patient Engagement in Neurorehabilitation

Charity Shelton, MS, CCC-SLP, CBIST
Mercy Neuro Outpatient Therapy Services
Springfield, MO

Disclosures

- I am a Mercy Hospital employee.
- I will be talking about my experiences with patients, families.
- I have signed consent forms to share video, patient information as part of this presentation.
- I have no other financial relationships to disclose. I do have a close family member who has a TBI.

Overview

- What is it, and why is it important?
- Impact on quality of service
- Interaction techniques that can maximize patient engagement

  -Considerations for acquired neuro injury

  -Importance of considering patient demographics in engagement
- Importance of family, support person engagement

Patient Engagement

WHAT IS IT AND WHY IS IT IMPORTANT?

Definition:

"Actions individuals must take to obtain the greatest benefit from the health care services available to them."

Center for Advancing Health, Washington, DC

Patient Engagement

It is characterized by behaviors of patients versus only the decisions, actions of providers, professionals.

Patient Engagement

It is NOT synonymous with compliance.

Compliance is doing what the provider commands.

Engagement is when a patient considers and combines professional advice with his or her own desires, goals, needs, etc.

Definition continued…

- The definition is COMPLEX and differs for patients based on age, ethnicity, culture, education level, medical diagnoses, and care setting.

- Of course patient engagement is critical to successful rehabilitation

Why is it important?

- "Patients and their families are essential partners in the effort to improve the quality and safety of health care. Their participation as active members of their own health care team is an essential component of making care safer and reducing readmission."

- *Centers for Medicare and Medicaid Services*

CMS

- Medicare conducts several pay-for-quality types of assessments that affect reimbursement rates.
- A proven method to improve patient outcome, is to get them more engaged in their healthcare and for that reason it is one of the six National Quality Strategy priorities, and a primary goal for CMS.

Patient Experience

- A patient's experience with a healthcare provider is influenced by that provider's ability to make the patient feel engaged and a part of their own recovery.
- Of course this affects patients' perceptions of quality of service and value of that service.
- Ultimately, all this affects patient outcomes.

Impact on Quality and Value of Service

Quality of Healthcare

- Price/cost is the top reason for consumers making purchase decisions for every industry EXCEPT healthcare.
- **Personal experience** is the top reason consumers choose a hospital or healthcare providers. This is 2 and ½ times more important to consumers than with other industries.

- *PWC Customer Experience Radar, 2012*

Improving Quality of Healthcare PWC Customer Experience Radar

- Understand your customers and their preferences.
- Encourage customer feedback
- Go above and beyond what's expected
- Invest in training managers and employees in customer service
- Train employees in being empathetic

Patient Engagement

In order to be successful, the following MUST be part of our interactions with our patients:

- Empathetic listening
- Nurturing relationships

Patient Engagement

- Personalized care that considers the patients right where they are
- Making recommendations as easy to understand and follow as possible.
- In the best therapeutic relationships, both the therapist and the client are invested

Patient Engagement

Benefits of engaged patients:

- They are more proactive in their care and recovery
- They are more invested in their treatment
- They understand their treatment as a part of their overall health and wellbeing
- They are more likely to complete home programs and suggestions
- They are more likely to research their treatment options and seek out the best clinicians

2015, Business

Patient Engagement Strategies

Patient Engagement

Patient Engagement

You can establish good patient engagement and relationships through:

- Motivational interviewing: it helps to promote positive behavioral change in the patient
- Therapeutic relationships: help promote "authentic connections" with our patients

Motivational Interviewing

Therapeutic Relationships

Motivational Interviewing

- It is a client-centered method in which a provider is attempting to promote internal motivation within a patient for positive change or improvement.

- Motivational interviewing is non-judgmental, non-confrontational and non-adversarial.

Miller, et al, 1992

Motivational Interviewing

- Should not be confused with imposing change on behavior but rather the patient's internal motivation for change. Miller, et al, 1992.
- Warmth, genuine empathy, and acceptance are necessary to foster therapeutic gain
- Rogers, 1961

Motivational Interviewing

- Of course this does not work for all patients, and some are more difficult for others, but motivational interviewing components should be used in all your patient interactions.
- Doing this will help to establish therapeutic relationships with your patients.

Important Processes

- **Engaging**: patient and provider relationship is based on trust and respect. When possible client should do most of the talking, with provider using reflective listening. It should be a collaboration to reach goals.

- **Focusing**: the ongoing process of seeking and maintaining direction.

Richard, Miller, William R. 2013

Motivational Interviewing

- **Evoking**: eliciting the client's own motivations for change, while evoking hope and confidence.

Important Processes

- **Planning**: involves the client making a commitment to change, and together with the provider, developing a specific plan of action.

Richard, Miller, William R. (William (2013)

OARS (Miller, W. R., & Rollnick, S., 1991)

- **O**pen-ended questions
- **A**ffirmation
- **R**eflective listening
- **S**ummaries

OARS for Motivational Interviewing

- **O** = Open-Ended Questions: These are not yes/no questions. Patient should be encouraged to "think out loud" while they consider your questions.

- *"Why are you in the hospital?" "What is your understanding of why you are getting therapy/receiving care from me?" "What did you think about that?"*

OARS

- **A** = Affirmation: This helps the patient feel like a partner in the therapeutic relationship. Affirmation is especially important when the patient is saying something you don't want to hear.

- *"I know you feel like you don't have time to do the exercises…" OR "I can tell you've been working on … I'm really impressed"*

OARS

- **R** = Reflective Listening: Listening is a very important part of the therapeutic relationship. It allows your patient to feel heard and ensures you've heard them correctly.

- *"You know that you need to get better to leave the hospital, but you feel like therapy won't make a difference."*
- *"You feel your pain is less when in that position but it hurts when…"*

OARS

- **S** = Summaries: Provider and patient review care in a collaborative manner. Review goals/progress, continued defcits, plans for future interventions.

- *"So if I understand all that you're telling me, you want…. Did I hear you right? What do you think about our time today?"*

Engaging Patients with Neurological Impairments

Tell me and I forget. Teach me and I remember. Involve me and I learn.

- Benjamin Franklin

Patient/Survivor Perspective

Insert video of Brent

This population **IS** more challenging

- Patients with CVA are often older and require consideration relative to their age
- Patients have communication impairments making interactions more challenging
- Patients have cognitive impairments affecting memory, reasoning, awareness of deficits
- Frontal lobe damage affects executive function and planning abilities

How you **communicate** with patients who are neuro-impaired population DOES matter!

Shelton & Shryock, 2007

- 102 videotaped interactions between individuals with brain injuries and staff

Subjects:

- 36 staff members, mostly comprised of PT, OT, Speech therapists; some nursing and physician interactions
- 36 individuals with neurological injuries: TBI (N = 23), stroke/CVA (N = 10), anoxic brain injury (N = 3)

Top 3 strategies that aided communication with patients whose cognitive-linguistic abilities were **severely to profoundly** impaired

- Use of short, simple sentences / directions
- Repetition of information / requests
- Clarification of the patient's communication attempts

Top 3 strategies that aided communication with patients whose cognitive-linguistic abilities were **mildly to moderately impaired**

- Facing the patient and making eye contact
- Clarifying the intent of patient's communication attempt
- Allowing the patient extra time to respond to questions and directions

What was the correlation between use of communication strategies and the success of the interactions?

As more strategies were used the success ratings for the interactions increased

PEARL: McMorrow, 2007

P: Positive

As the professional, you should remain positive and upbeat.

Avoid negative communication.

PEARL

E = Early:

Don't wait for situations to get difficult; anticipate and act early. Behavior analysis involves "preventing" negative or unwanted behaviors by implementing proactive communication and interventions.

PEARL

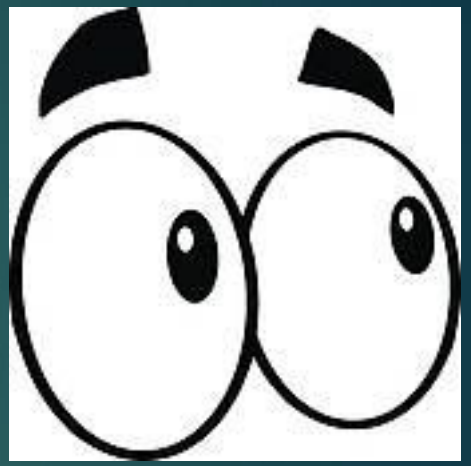
A = All:

interact with all patients at all times in all situations; unless a patient is trying to physically harm you, there should be no exception to this. Never avoid interactions, especially in stressful situations. Unconditional regard for all patients at all times.

PEARL

R = Reinforce: reinforcing interactions can result in desired behaviors; not the same for all. What's important in stressful, challenging situations is they you are reinforcing appropriate behaviors so they occur more often. Most patients want to interact with you and when you communicate with them, it is positive reinforcement.

PEARL



L = Look: "listen" and look for opportunities to praise. Look for opportunities to intervene and prevent a situation from becoming bad or stressful. Whenever interacting with person who has challenging behaviors, always look and listen for information that may give you ideas for specific interventions to manage behaviors.

Interactions with Patients Who Are Verbally Aggrssive CPI, 1997

Don't

- Make demands
- Compromise privacy
- Rush the patient to make decisions
- Get into power struggle
- Argue
- Raise your voice
- Become defensive
- Belittle

Do

- Be empathetic
- Be respectful
- Allow time for processing
- Set limits
- Give choices
- Provide both positive and negative consequences

Response to Anger Outbursts

Luterman, 2008

For angry, verbal attacks:

- Respond with unconditional positive regard
- Maintain poise
- Be aware of defense mechanisms
- Maintain good eye contact
- Listen without interrupting
- Allow patient time to blow off steam

Response to Anger Outbursts

Richmond, J, Berlin, J., et al, 2012

- Respect personal space
- Do not be provocative
- Establish verbal contact
- Be concise
- Identify wants and feelings

Verbally Aggressive: Response to Anger Outbursts

Richmond, J, Berlin, J., et al, 2012

- Listen closely to what the person is saying
- Agree or agree to disagree
- Lay down the law and set clear limits
- Offer choices and optimism

-"you can do this or this"

-"would you like this or this"

Offer what you would rather them choose or do as last option.

Response to Anger Outbursts

- Pause before responding – this can allow time for person to process their own words, actions
- Offer empathetic statements or reflections of feelings
- Affirm patient's feelings of frustration/anger
- Allow person to respond more appropriately

Response to Anger Outbursts

- Allow patient to "save face"
- Help patient to feel validated and important by returning to therapy tasks that will allow success

Confrontation and argument WILL result in disengaged patient.

Respect and affirmation despite disagreement will result in engaged patient.

Consider Socioeconomic Status in Engaging Patients

- Research suggests that active participation from patients is strongly associated with socioeconomic demographics
- Patients' participation is directly related to their prior expectations of a health-care consultation and this is often based on their cultural expectations and social positions.

- Plotheroe, et al, 2013

- Patients with lower socioeconomic status have considerably lower rates of good functional outcome after stroke
- Higher education results in better participation and better functional outcomes, including return to work

Grube, et al 2012
Fernandez, et al, 2012
Brey & Wolf, 2015

So…what do we do?

- Always include questions about highest level of education in your intake interviews
- Be sure to ask the patient his/her goal for therapy and help balance any unrealistic expectations up front
- Ensure that therapeutic regimen, home program tasks are easy to understand, relevant to patient, and related goals are achievable

Family Engagement

Kristi's Perspective (insert video)

Importance of Family Engagement

It is **VERY** important to success of survivor to:

- Involve family in decision making
- Being able to interact with them
- Gaining trust of family
- Having them support what you're trying to do in rehab
- Assist family in the coping and grieving process

Family Types

- The "Too Involved/ Demanding" family
- The "Not Involved at All" family
- The "Want to Do Everything for the Patient" Family
- The "Dysfunctional" Family
- The "Unrealistic Expectations" Family
- The "Educable, oh So Easy" Family

"Too Involved/Demanding"

This is the family that wants to dictate how everything should be done – medical, rehab, and otherwise

This family needs:

- LOTS of communication at all times – make them feel part of the team (family conference)
- "Manage up" – ensure excellent care by staff
- Permission to take a break from patient care/ responsibility
- Need "direction" for doing research on their own
- Clear boundaries for what they have control over as a family member and what decisions the treatment team will make. May be asked to come only during specified hours.

"Not Involved at All"

This is the family that is never present for therapies, does not return phone calls, and does not visit the patient.

This family needs:

- Treatment team needs to establish whether family will or won't be involved after patient discharges (family conference)
- Consistent attempts to communicate – via social worker, family conferences, paper documentation or emails of patient progress, DC plan, etc.
- An established time for family training with all appropriate staff members as needed
- If this family insists on taking survivor home but has not participated in communications, trainings, etc., a call to family services may be deemed necessary

"Do-Everything-for-the-Patient"

This family is typically present all the time and interferes with the team's assessment of the patient's independence b/c they do everything for the patient.

This family needs:

- Up-front communication about what is expected of their involvement (family conference)
- Rationale for why it is important to maximize independence in the survivor
- "Proof" the patient has the ability to do some or all of tasks without their help
- Training for appropriate cueing, set up techniques to maximize independence (while still feeling involved with the survivor)
- If the above does not work, may request that family only be present during specified hours/times of the day.

"Dysfunctional"

This is the type of family that had many challenges/ dysfunction even before the survivor had their injury (i.e., drugs/alcohol, divorce, family relationship issues, financial challenges, etc).

This family needs:

- Communication about focusing on the needs of the survivor after injury, not "all the other stuff" (family conference)
- Specific instructions on not bringing the "issues" to the patient (via phone calls, visits, etc).
- Education about how the mental/emotional systems of survivors being reduced after neuro-injury
- Consult with neuro-psych for family counseling may be needed

"Unrealistic Goals"

This family feels the survivor will recover to be the person they knew before the injury. This is the expectation, and they expect the person not to leave rehab until they are "fixed."

This family needs:

- LOTS of education about brain injury recovery and prognosis
- May need concrete proof, research that shows numbers on recovery
- Show them what the survivor "can" do within their limitations
- May benefit from family education group, especially with other family members who are appropriately dealing with limitations of loved ones
- Explanation of medical treatment/billing ethics
- Family conference to specifically discuss length of stay, amount of recovery expected, discharge recs (given from the beginning of rehab)

"Educable, oh So Easy"

This family is fully cooperative, does all that is requested by the team, has realistic expectations. (May have no questions – this could be a good or bad thing).

This family needs:

- Staff to make sure all questions are answered – don't wait for them to ask – just tell them.
- Contact information at discharge (because although they may have no questions at the time, they may have many after taking the survivor home).
- May benefit from a follow-up phone call after DC

Research and Family Perspective

What does research tell us about family satisfaction with communication from service providers ?

Research Findings

Families Dislike

- Many different people providing information
- Restrictive visiting hours in a facility
- No written information

Families Like

- 1 or 2 people providing information
- Open visiting hours
- Pamphlets/written educational materials

Johnson, et al, 1998

Henneman, et al, 1998

Friedemann-Sanchez, 2008

Research Findings

Dislike

- Unclear, ambiguous information
- Providing no information on prognosis
- Insufficient education/information at time of transition

Soderstrom, et al, 2006

Friedemann-Sanchez, 2008

Kolakowsky-Havner, 2001

Like

- Clear, unambiguous information
- Hearing prognosis as soon as possible, even if it's a poor one
- Education/information to help in transition times post injury

LeClaire, et al, 2005

Rotundi, et al, 2007

Research Findings

Dislike

- Lack of emotional support
- Adversarial interaction with providers

Sinnakaruppan & Williams, 2001

Kolakowsky-Havner, 2001

McMordie, 1991

McLaughlin, 2008

Like

- Emotional support
- Consistent, respectful interaction, despite any differences in opinion between family and providers

Interacting with Families

- Face-to-face is ALWAYS best
- Be a good listener
- Be affirming
- Don't question a person's beliefs/spirituality
- Don't say you understand
- Instead of telling someone they're wrong – instead, say things like…"in my experience…" or "research to date has shown…"

Family Education/Interactions

- Tell them, tell them again, and tell them 1 more time.
- Families will accept information and/or retain it, depending on where they are in the recovery and/or coping process.
- Be simple and as concrete as possible
- When educating the family on how to interact with survivor, model appropriate interactions.

Family Education/Interactions

- Have family sit in for therapy sessions when appropriate
- You never know what someone's lashing out might indicate.

Do/Don't

DON'T

- Assume you shouldn't explain something because you think the family already knows it
- Use too much medical jargon

DO

- Explain things as many times as appropriate or needed
- Explain in simple terms and be sure to check that they understand

Do/Don't

DON'T

- Deny families hope
- Be completely unemotional when interacting with families

DO

- Provide honest, clear information
- Try to have a "happy medium" between professionalism and having empathy for a family's situation

Do/Don't

DON'T

- Be adversarial with families
- Be resistant to communicating with family

DO

- Be respectful and honest, despite differing opinions between you and families
- Always have open lines of communication and be willing to explain anything

Do/Don't

DON'T

- Dismiss family members' suggestions because you think that they're not the "expert"
- Assume the survivor is the only one affected by their injury

DO

- Make it a priority to ensure that family members are an integral part of the treatment team
- Realize that the entire family is affected

In Summary:

- Partnerships with our patients and their families should be a priority for all of us!

- Engaged patients and engaged families = maximal improvement with excellent outcomes

"Communication does not depend on syntax, or eloquence, or rhetoric, or articulation but on the emotional context in which the message is being heard. "

EDWIN H. FRIEDMAN

THANK YOU!

charity.shelton@mercy.net