Transforming Mental Health Care Systems Through Health Literacy
Catina O’Leary, PhD, LMSW
HLM President and CEO

Michelle Roberts, M.Ed., MSJ, PLPC, NCC
HLM Director of Communications, Strategy and Market Research
Catina O’Leary

**Credentials**

PhD in Social Work and Licensed Master Social Worker (LMSW)

**Experience**

Prior to HLM, Catina worked in traditional mental and behavioral health, substance abuse, and psychology related to occupational therapy.

**More...**

Catina has been involved in behavioral and community mental health her whole life; her mother ran a treatment network for 20 years.
## Michelle Roberts

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<th><strong>Credentials</strong></th>
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<td>o M.Ed. in Clinical Mental Health Counseling</td>
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<td>o Provisionally licensed clinical mental health counselor (PLPC)</td>
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<td>o PhD Candidate in Counselor Education</td>
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What is health literacy?

An intersection of communication factors that affect health
In 2014, an estimated 9.8 million adults aged 18 and older in the U.S. had a serious mental illness (4.2% of all adults).

Nationally, 57% of adults with mental illness receive no treatment, and in some states that increases to 70%.

SAMHSA, 2014; Mental Health America, 2016, Employers Health, The National Academies, 2009
Serious mental illness, major depressive disorders, and alcohol and illicit drug use are among the top conditions that cause disability and carry a high burden of disease in the U.S.

More people miss work because of mental illness than any physical condition like cancer and heart disease. Depression alone costs employers $44 billion annually in lost productivity.

The financial costs in terms of treatment services and lost productivity are estimated at $247 billion per year.

SAMHSA, 2014; Mental Health America, 2016, Employers Health, The National Academies, 2009
<table>
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<th>Mental health in the U.S.</th>
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<td>1</td>
<td>Symptoms usually present by late childhood or young adulthood</td>
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<td>2</td>
<td>A quarter of the US population reports mild symptoms of psychological nature</td>
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<td>3</td>
<td>The median treatment delay is 10 years</td>
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<td>4</td>
<td>Delayed treatment increases likelihood of other illnesses</td>
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People with serious mental illness die 25 years earlier than the general population.
Mental illness can block health care

Less access to health care due to:

- **Patient factors:** Amotivation, fearfulness, social instability
- **Medical provider factors:** Competing demands, stigma, poor training on how to communicate with people with mental illness
- **Behavioral health provider factors:** Trained “communicators,” but not versed in health literacy principles
- **System factors:** Fragmentation

Parks et al., 2006
Increased risk for death from preventable disease

People with serious mental illness are more likely to die from:
- Cardiovascular disease
- Diabetes (including related conditions such as kidney failure)
- Respiratory disease (including pneumonia and influenza)
- Infectious disease (including HIV/AIDS)
Factors that increase risk

These vulnerabilities are amplified due to:

- Social factors
- Stigma
- The impact of mental health symptoms
- Mental health symptoms that mask symptoms of medical illnesses
- Psychotrophic medications
- Polypharmacy
- Lack of access to appropriate health care and
- Lack of coordination between providers

Parks et al., 2006
Barriers to communication

What symptoms interfere with someone’s ability to communicate?
- Increased anxiety
- Paranoia
- Decreased attention or concentration
- Superstitious thinking
- Voices

History of “Trauma” from Treatment
- Actual traumas
- Perceptions of trauma
How mental illness can affect thinking
More barriers to communication

**Low Self-Efficacy**
- I don’t believe I can do it
- Why should I try?
- This isn’t going to help!
- What good is therapy going to do?
- I’ve tried medications before, nothing helps

**Low Self-Esteem**
- No one can help me
- A case manager can’t help me
- I’m not worthy of help
- These doctors don’t care about me
Persons with serious mental illness and multiple chronic medical conditions often have many, many different healthcare providers and take many different medications.

Dr. Joe Parks, Missouri Department of Mental Health
Doctors assume that we’re not reliable witnesses to our own health care.

IBP Partners in Health Interagency Toolkit, 2013
What mental health clients are saying about...
their experiences with physical health care

I feel like I’m being rushed out and don’t have time to tell them what’s happening .... I say, “I’m here. At least let me tell you.”

IBP Partners in Health Interagency Toolkit, 2013
What mental health clients are saying about their experiences with physical health care

They should look the patient in the eye....Listen to what’s really going on with that person.
What mental health clients are saying about…

their experiences with mental health care

Sometimes people in mental health think your brain is broken, and they treat you like that.
What mental health clients are saying about their experiences with mental health care

They should look the patient in the eye.... Listen to what’s really going on with that person.
When you walk into a visit with the psychiatrist, they have nine minutes for you. They recommend a particular drug or two or three, and if the client has any questions, the answers are terse and they gloss over some of the most important risks.
What mental health clients are saying about…

their experiences with mental health care

I got really scared because who would take a list of meds for something they haven’t even been educated about.
What do clients want from their doctors?

- Allow them two minutes to talk before interrupting
- Explain the illness, its importance and impact in their words
- Provide them with written information they can understand
- Explain medications and address their concerns

IBP Partners in Health Interagency Toolkit, 2013
What do clients want from their doctors?

Don’t assume that their symptoms are all in their head

Link treatment to clients’ recovery goals

Offer and encourage participation in peer support groups

See them as a whole person

IBP Partners in Health Interagency Toolkit, 2013
We stigmatize things we don’t know what to do about. [Medical doctors] don’t know what to do about mental illness, so they send that to somebody else.
Clients feel stigmatized by their providers

**Why?**

- The orientation of primary care is reactive
- Physicians may be inexperienced, uncomfortable or biased (some fear mental health clients are incompetent, dangerous, unmotivated or uneducated)
- Physicians don’t have enough time:
  - To discuss psychological issues
  - To complete physical assessments
- Physicians communicate their discomfort to clients
Why should providers care about stigma?

Perceived stigma results in:
- Lower medication adherence
- Treatment drop-outs
- No shows
- Fewer people accessing mental health care
- Lack of physical health care

Parks et al., 2006
Strategies for health-literate mental health care

What kinds of techniques help to decrease risks and increase understanding and action?

1. Health Environment Assessments
2. Plain language in written materials and speaking
3. Symptom-based communication strategies
4. Empathy
Our partnership with Truman Medical Centers

About Truman Medical Centers Behavioral Health
- Largest provider of mental health services in the Kansas City metro region
- Serves over 18,000 patients each year, with over 200,000 outpatient visits

Health Literacy Missouri’s role
- We are partnering with Truman Medical Centers to provide:
  - Plain language workshops for providers
  - Plain language document review and creation
  - Health Environment Assessments
- Currently completed 75% of the grant
1 Health Environment Assessments
Assessment:
Record observations on a digital checklist that allows for real-time capture of data and photographs

Report:
Write individual facility reports, including observations, photographs, strengths, and evidence-based recommendations

Use the information:
- Debrief sessions with staff
- Informed training and document development
System barriers we identified

Unclear navigation
- Increases anxiety, stress and anger in patients
- Reduces efficiency of clinical staff

Poor design
- Contributes to wayfinding problems and can increase anxiety
- Does not support healing and recovery

Unclear materials
- Loss of self-efficacy and confidence
- Main message gets lost in lengthy or disorganized documents

Unclear communication
- Patients may not understand diagnosis or treatment options
- Patients may feel concerns are ignored

Robert Wood Johnson Foundation, 2004; Farrisi, 2012; Health Literacy Missouri, 2009; Lin, 2011; DeWalt, et. al., 2010
Assessment with mental health focus

Unclear navigation
- Stress from being lost can negatively influence a patient’s mental health, functional ability and safety

Poor design
- Poorly designed facilities can reinforce negative behavior, promote self-injury and increase a patient’s compulsive and obsessive tendencies

Taylor, 1996; Shepley, 2013
Assessment with mental health focus

Unclear and irrelevant materials
- Stigma and complicated information can negatively affect how they understand their condition
- Materials that are not tailored to the population are not helpful

Unclear communication
- Mental health patients are more likely to have low health literacy
- Misunderstanding can negatively affect the attitude and behaviors of a mental health patient
Navigation to the facility

Results:
- Many of the facilities either lacked an accurate Google profile or lack of exterior signage clearly labeling the building

Recommendation:
- Update Google profile and give clear address information on the website and building

Implications:
- Accurate and clear address and directional information can help set patients up for success

We had trouble navigating to 4 out of the 5 facilities we assessed.

80%
Navigation within the facility

Results:
- Wayfinding system at most locations did not exist or had unclear signage
- Signs were not written in plain language and used unfamiliar acronyms

Implications:
- Good wayfinding promotes healing
- Comprehensive wayfinding systems include various types of signs and use plain language best practices

Recommendation:
Develop a wayfinding system to help clients

4 out of 5 of the facilities lack a developed wayfinding system
Patient-centered design

Results:
- Open-top cubicles and rooms without a ceiling threaten patient privacy
- White noise machines utilized are not effective enough

Implications:
- Threats to privacy may make patients feel it’s not a safe space to talk
- Lack of privacy may be an issue with the HIPAA law

Recommendation:
White noise machines and specialist consultation

2 out of 5 of the facilities had serious privacy concerns
2 Use of Plain Language

- Written materials
- Spoken conversation
Interventions: reviewing documents

- Reviewed and revised 100 pages of existing patient-facing documents
- 90-minute workshop with TMCBH staff who write and revise documents for their department
  - Trained on plain language principles
  - Practice reviewing a TMCBH document
  - Develop sustainability for the organization
The need for plain language

Health care providers often use medical jargon that’s unfamiliar to most people.

Education materials are written beyond most people’s ability to understand.

Parler and Ratzan, 2010
In one study, 54 percent of clients in an urban psychiatric clinic had limited reading skills.

Another nationally representative sample showed that 75 percent of people with self-reported mental health problems had limited reading skills.

Mental illness + low literacy = double stigma
Plain language principles

- Focus
- Structure
- Content
- Behavior
- Design
Health literacy takeaways

Improve high-use patient education documents to be:

• Easy to read and understand
• Visually appealing
• Easy to use

Teach managers and key staff how to identify, revise and write documents that follow plain language principles
Need for patient education materials

- 80% of information is forgotten once people leave a doctor’s office
- 50% of the information people are able to recall is incorrect

(Kessels, 2003)
People with anxiety can experience a reduced working memory

Self-efficacy to manage Type II diabetes was found to shift with cognitive impairment

Balderson et al., 2016; Wykes et al., 2016
Interventions: creating and using documents

- Developed 50 pages of new patient education materials about high-use, high-impact topics

- 90-minute workshop with TMCBH staff about:
  - How to identify a plain language document
  - How to use a written document to support spoken communication
  - How to write instructions in plain language
Health literacy takeaways

- Staff need to know how to identify a health-literate document and choose accordingly.
- Staff need access to health-literate patient education documents.
- Staff need to use patient education documents to support spoken instructions, not replace them.
3 | Symptom-based communication
Helping people who hallucinate

- Never argue with the person
- Keep the environment quiet and calm
- Keep an eye on their safety and that of others
- Help their peers understand they are preoccupied
Remember these things:

- These sensations are very real
- Most hallucinations can be stopped or minimized with medication
- Some people live with their hallucinations quite well
- Some people are bothered by them but can function in society
- Some people respond to their internal stimuli without realizing it
What you can do

- Stay calmly present and aware
- Speak quietly, slowly and politely
- Give the person extra time to respond to requests
- Remember the person is under stress from trying to blend inner and outer worlds
Helping people when they are angry

To help a person during anger, you need to be:

- Very centered in compassion and a very good listener for just a few moments
- Focused on the present moment (not the end result)
- Focused on the person, not the story
- Aware that anger is self-limiting
- Respectful and willing to stay with the person as they calm down
## Helping angry people – “The Formula”

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<tr>
<th>Step</th>
<th>Description</th>
<th>Statement</th>
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<tr>
<td>1.</td>
<td>Take a deep breath &amp; center</td>
<td>“I can do this right now”</td>
</tr>
<tr>
<td>2.</td>
<td>Face the person directly</td>
<td>“I am available to you on this”</td>
</tr>
<tr>
<td>3.</td>
<td>Open your posture</td>
<td>“I am open to you &amp; not afraid”</td>
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<tr>
<td>4.</td>
<td>Cover your solar plexus</td>
<td>“I will not be hurt by your words”</td>
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<tr>
<td>5.</td>
<td>Use good eye contact</td>
<td>“I am paying attention to you”</td>
</tr>
<tr>
<td>6.</td>
<td>Repeat feeling statement</td>
<td>“I am really listening to you”</td>
</tr>
<tr>
<td>7.</td>
<td>Watch for the end</td>
<td>“I am glad you feel better”</td>
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</tbody>
</table>
People with depression may show the following behaviors in clinical settings:

- Usually cooperate in the ER, especially if there are no other psych issues involved.
- Tend not to ask for what they need or want.
- May or may not have intent to hurt self, may or may not want hospitalization vs. being set up with services.
- Poor sleep or hygiene, inability to function, impaired judgment, lack of motivation, difficulty making decisions.
- May be trying to please others vs. caring for themselves.
- Negative, unrealistic thinking.

Gilbert, 2009
What you can do

- Offer your full attention and sit with patients in silence if needed
- Use simple, concrete statements
- Make basic observations to initiate conversations
- Encourage patients to communicate with others
- Clarify information given by the patient

Garrett, Bormann, & Link, 2016
Communicating with people experiencing psychosis

People with a variety of mental health disorders may display psychotic symptoms:

- They will often misinterpret communication
- Typically don’t realize that their thinking is delusional or irrational
- May extend their paranoia to include staff
- May believe that others are reading their thoughts, secretly plotting against them
- May not be willing to share what they are feeling
- Can be very frightened and anxious but are not typically violent or aggressive to others

Gilbert, 2009
What you can do

- Approach patients in a caring, empathetic and non-judgmental way
- Focus on understanding the patient’s feelings behind the symptoms
- Focus the conversation on reality-based topics
- Use simple and concrete communication
- Be consistent and honest
- Be careful with how you communicate with other staff

Garrett, Bormann, & Link, 2016
Therapeutic communication helps people in distress

Therapeutic communication is a key component of patient-centered care. Techniques include:

- Offering time and attention to patients
- Allowing broad openings in the dialogue
- Giving information to the patient
- Clarifying information given by the patient
## Therapeutic communication techniques

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<th>Technique</th>
<th>Examples</th>
<th>Rationale for using this technique</th>
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<tr>
<td>Offer self (time and attention)</td>
<td>“I’m interested in spending time with you”</td>
<td>Shows interest in the patient, but doesn’t require them to respond. Effective with patients with severe depression or other illnesses</td>
</tr>
<tr>
<td>Allow broad openings and silence</td>
<td>“What would you like to talk about today?”</td>
<td>It asks the patient to provide narrative information and allows the patient to direct the conversation</td>
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<tr>
<td>Give information</td>
<td>“Dr. Smith’s office is on the third floor of the medical complex”</td>
<td>It helps patients participate in their care and allows the provider to be seen as a resource</td>
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<tr>
<td>Clarify information (through paraphrasing, exploring, reflecting, and restating)</td>
<td>“Tell me more about what was happening in your life when you first started drinking”</td>
<td>Help gather feedback on interpretation of what the client has told the provider and clear up any ambiguous messages</td>
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Adapted from: Garrett, Bormann, & Link, 2016
4 Use of empathy
The truth is, rarely can a response make something better – what makes something better is connection.

Dr. Brene Brown, Research Professor at the University of Houston
Empathy in caregiving

A cognitive attribute that involves an ability to understand the patient’s inner experiences and perspective and a capability to communicate this understanding.
Motivational interviewing process

Engaging
Use listening, accurate empathy, striving to understand from patient’s perspective

Focusing
Guiding patient to a target behavior that is important to them

Miller and Rollnick, 2009
Motivational interviewing process

Evoking
Draw out client’s intrinsic motivation and their own ideas for change

Planning
Consolidate commitment, assist with change plans and revisit change plans
Motivational interviewing principles

Feedback
Inform the patient about the risks and consequences of problematic behaviors

Responsibility
The responsibility to change lies with the patient. The patient then makes their own decisions.

Advice
The provider gives advice, but the patient ultimately makes the decision.
Motivational interviewing principles

**Menu**
Present the patient with options from which they can choose

**Empathy**
The counselor must convey a true understanding of the situation or dilemma

**Self-efficacy**
Discovering a patient’s past successful actions and increasing their confidence in their own abilities
The Sacred Moment

What is the Sacred Moment?
- A practice to put empathy back in caregiving
- “What is your biggest fear or concern about being in the hospital?”

What was its impact?
- Caregivers were re-inspired
- Patient satisfaction scores increased
My story...
- Please call me by this name:
- My support system includes:
- What gives me peace is:
- When I’m stressed I:

Because I matter...
- Today I am proud of:
- Today I am grateful for:
- I most hope for:
- My goals are:
- My main concern is:
- The most important thing I need answered is:
Moving forward
Moving forward

Recommendations at a national level
• Designate people with serious mental illness as a health disparities population
• Adopt ongoing surveillance methods
• Support education and advocacy

Recommendations at a state level
• Improve access to physical health care
• Promote coordinated and integrated mental health and physical health care for people with serious mental illness
• Address funding for these initiatives

Parks et al., 2006
Moving forward

Recommendations for provider agencies and clinicians
• Adopt as a policy that mental health and physical health care are integrated
• Help individuals understand the message of recovery
• Implement care coordination models

Recommendations for families and communities
• Encourage people we serve, families, and communities to develop a vision of integrated care
• Encourage advocacy, education, and successful partnerships
• Pursue individualized person-centered care that is focused on recovery and wellness
Recognize the relationship between mental health and health literacy

- Those with low health literacy tend to:
  - have poor health status
  - use emergency rooms more frequently
  - have a higher risk of death
- These problems are multiplied exponentially for those with serious mental illness

Work with mental health systems to integrate health literacy interventions into daily practice

- Train medical staff on communication strategies to increase patient understanding
- Assess health systems and apply targeted health literacy best practices
- Educate those who develop health-related documents to use plain language best practices
People with serious mental illness die 25 years earlier than the general population.

People with serious mental illness face many barriers when they try to access health care services.

Use these strategies to lower risk and increase understanding:

1. Health Environment Assessments
2. Plain language in written materials and speaking
3. Symptom-based communication strategies
4. Empathy