Research Professionals Network Workshop Series

Having Difficult Conversations/Words Matter

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Aims of this Presentation

1. Provide education on stigmatizing language and how to audit research documentation.
2. Develop skills to address participant conflicts with greater empathy.
3. Help research staff identify ways that research teams can address issues of sensitivity with regards to language and create a healthy environment surrounding language used in the research space.
4. Know what resources are geared towards staff at our institutions to help educate and address stigmatizing language and improve the communication of researchers and health care providers.

Stigmatizing Language

- Perceived *control* that a person has control over a condition
- Perceived *fault* in acquiring a condition
- Stigma comes in a variety of forms
  - Defining characteristic of an individual (e.g. alcoholic, drug addict)
  - Derogatory language (e.g. crazy, insane)
  - Sensational or fear-based language (e.g. referring to emerging drug threats as "unlike anything ever seen before")

Types of Stigma

- **Personal.** Self-disgust, shame, and self-hate at one's own appearance, behavior, lifestyle, and or/physical condition
  - Someone might not reach out to available resources or help because they feel helpless
- **Social.** Feeling isolated or rejected because of negative perceptions, labels, and actions
  - Labeling, stereotypes, division of us v. them, discrimination, "deadnaming"
- **Institutional.** Negative treatment and attitudes from healthcare providers, media, law enforcement, etc.
  - Patients incur higher out-of-pocket costs for mental health services than for other types of medical care → Patients have difficulty navigating systems to access care or avoid seeking help
  - Poor reimbursement for mental health practitioners → Practitioners choose not to accept insurance or low-income patients
  - Provider bias could also lead to institutional stigma
    - Not screening or referring for depression if they think it is not a "real" condition → Clinic/hospital where people with depression will get systematically overlooked and blocked from evidence-based care

Stigmatizing Language/Outdated Language	Appropriate/Empowering Language
Psycho, Crazy, Insane e.g. "He is acting like an insane person,""my ex-girlfriend was such a psycho" Actual quote from a clinician asked about referring patients for a schizophrenia study: "That patient is definitely crazy, so is that one, you could get a medal if you can get her in your study since she is super crazy."	**Person with a psychotic disorder, person with psychosis** Refraining from describing someone who acts erratically or in a way that makes them "difficult" as having psychosis, using having a psychotic disorder or a mental health disorder as an insult
Mental Retardation (outdated term used in older versions of DSM) remains in <u>a lot</u> of medical records	**Intellectual Disability** (medically accurate term per new guidelines)
Non person first language (Autistics, Schizophrenic)	**Person first language** e.g. Person with schizophrenia, people with Autism
"Oh, like the guy in (insert movie name)" e.g. "Oh, like the guy in *Rain Man*," "Like the *Beautiful Mind* guy," "She's like Angelina Jolie in *Girl, Interrupted*"	Refer to up to date medical and academic literature Let research subjects tell you what their diagnosis and life experience consists of

Tips to Avoid Stigmatizing Language

1. Performing language audit
2. Seek input from others to see if the language is appropriate and respectful for the intended audience
3. Train staff on issues related to stigmatizing language, including the important negative health and community outcomes relating to perpetuating stigma
   a. MA Department of Public Health Campaign #StateWithoutStigMA
      i. Stories of Stigma https://www.mass.gov/service-details/stories-of-stigma
   b. Boston Medical Center's Grayken Center for Addiction
      i. Words Matter pledge

Performing a language audit

1. Person first language (e.g. drug abuser v. person with SUD)
2. Technical, clear language v. colloquialisms (e.g. negative urine drug screen v. clean urine)
3. Sensational or fear-based language (e.g. referring to emerging drug threats as "bigger" or "scarier")

Activity 1: Language Audit

Instructions
1. Split up into small groups and follow the instructions below.
2. We will discuss the narrative as a whole.

For Sections 1 and 2:
1. Identify examples of stigmatizing language in the form.
2. Provide examples of how to rephrase the sentence(s).

Section 1:
Mr. R is a _28-year old man with sickle cell disease and chronic left hip osteomyelitis_ who comes to the ED with _10/10 pain_ in his arms and legs. He has about 8-10 pain crises per year, for which he _typically requires opioid pain medication in the ED_. At home, _he takes_ 100 mg OxyContin BID and oxycodone 5 mg for breakthrough pain. Over the past few days, _he has_ taken 2 tabs every 4-6 hours. About 3 months ago, _he moved to a new apartment_ and now has to wheel himself up in a manual wheelchair up 3 blocks from the bus stop.

He spent yesterday afternoon with friends and wheeled himself around more than usual, which caused dehydration due to the heat. He believes that this, along with _recent stress_, precipitated his current crisis. The pain is aching in quality, severe (10/10), and not alleviated by his _home pain medication regimen_.

On physical exam, he is in obvious distress. He has no fever and his pulse ox is 96% on RA. The rest of the physical exam is normal _other than tenderness to palpation on the left hip_.

Section 2:
Mr. R is sleeping but easily arousable and _seems distressed_. He is _not tolerating the oxygen mask_ and _still has 10/10 pain_. His girlfriend is by his side but _will need to go home soon_.

Example of Stigmatizing Language in the Medical Record - Goddu, et. al. (2018)

- 223 physicians-in-training (i.e. medical students, residents) in internal and emergency departments in an urban academic medical center
- Randomized vignette study of two chart notes with stigmatizing v. neutral language
- Describe the hypothetical patient (28-year-old man with sickle cell disease) and determine pain management decisions
- Key Results
  - Exposure to the stigmatizing language note was associated with more negative attitudes and less aggressive management of the patient's pain
  - Highlights the importance of word choice

Addressing Participant Concerns

What types of difficult conversations have you had with study participants?

- Stigmatizing language in a consent form
- Not eligible for the study
- Reporting abnormal lab test
- Unanticipated events
- Protocol deviations

Addressing Participant Concerns
Using empathy

- May not calm your participant down quicker
- Can enable patients to feel
  - that you are with them
  - that you care
  - that you can tailor what you talk about for their benefit

Addressing Participant Concerns

Responding to Emotion: Articulating empathy using NURSE statements

	Example	Notes
Naming	"It sounds like you are frustrated"	In general, turn down the intensity a notch when you name the emotion
Understanding	"This helps me understand what you are thinking"	Think of this as another kind of acknowledgment but stop short of suggesting you understand everything (you don't)
Respecting	"I can see you have really been trying to follow our instructions"	Remember that praise also fits in here (eg- "I think you have done a great job with this")
Supporting	"I will do my best to make sure you have what you need"	Making this kind of commitment is a powerful statement
Exploring	"Could you say more about what you mean when you say that…"	Asking a focused question prevents "exploring" from seeming too obvious

Addressing Participant Concerns
Responding to Emotion: Fundamental Skills

Start a Conversation:	Example	Notes
Tell me more	"Tell me more about…"	Use when you are not sure what someone is talking about (rather than jump to an assumption).
Ask-tell-ask	"What do you think about…" "Here's what the tests show" "Does that make sense…?"	Think of this as one unit of information transfer
"I wish" statements	"I wish I could say that the chemo always works"	Enables you to align with the patient while acknowledging the reality of the situation

Activity 2:
Addressing Participant Concerns

- Stigmatizing study titles in medical record

- Example:
  - A Phase III, Randomized, Double-Blind, Active Controlled, Parallel Group, Multi-center Trial Assessing the Efficacy and Safety of a Once-Weekly and Once Monthly, Long-Acting Subcutaneous Injectable Depot of Buprenorphine in Treatment of Adult outpatients with Opioid Use Disorder

Activity 2:
Addressing Participant Concerns

- A Phase III, Randomized, Double-Blind, Active Controlled, Parallel Group, Multi-center Trial Assessing the Efficacy and Safety of a Once-Weekly and Once Monthly, Long-Acting Subcutaneous Injectable Depot of Buprenorphine in Treatment of Adult outpatients with Opioid Use Disorder

- Scenario: One of the study participants is very upset to learn that their participation in this study is known to anyone looking at their medical record.
- What NURSE statements and fundamental skills would be helpful in this scenario?

Activity 2:
Addressing Participant Concerns

- Tell me more
  - Tell me more about how seeing that title made you feel.
- Ask-tell-ask
  - Are you telling me that seeing the title in your medical record made you feel...?
  - As a safety measure, we include study titles in the medical record.
  - Would removing the title or renaming the title address your concerns?
- I wish
  - I wish I could tell you that no one else will see this. But I will immediately ask the investigator to make the appropriate request to have it removed and will tell you when it has happened.

Addressing Participant Concerns
Serious News - Breaking bad news using the GUIDE tool

Get Ready: Info, people, place	"Let me take a minute to make sure I've got what I need." Make sure you have all the information you need at hand Make sure you have all the right people in the room Find a place with some privacy
Understand what the patient knows	"What thoughts have you had since the biopsy?" "What have you taken away from other doctors so far?"
Inform starting with a headline	"The CT scan shows that the cancer has gotten worse" Give the information clearly and to the point with a one-sentence headline of the most important piece of information you want them to take away Avoid jargon After the headline you will need to give more information, but after giving the headline, STOP!
Dignify emotion by responding directly	"I can see this news is not what you were hoping for." Expect the patients first response to be emotion Acknowledge the emotion explicitly.
Equip the participant for the next step	"Is there anything I could do to make this a little easier?" "I want you to be prepared for the next step. Can I explain…" Don't dismiss concerns or say that everything will be fine.

Reasons Why Stigmatizing Language Is Used Sometimes by Researchers

- Someone may be used to the names of diagnoses that were once used but became outdated
  - Old term is seen as stigmatizing
- Pop culture and mainstream culture outside of the medical field use certain terms or language that are stigmatizing or not appropriate for the medical field
- Have truly never heard that a certain term was inappropriate or harmful
- Belief that this is something "Millennials" get frustrated about that doesn't seem like it should be such a big deal
- Received research and academic training in environments where this language was used by PIs, professors, and/or clinicians
- Someone has maybe wondered if language is stigmatizing but no one has ever said they take issue, so must not be that bad
- Research subjects sometimes self identify with certain language (e.g. "I'm an addict")

Providing One-on-One Feedback

Do:

- Find a quiet and private place to discuss concern
- Be specific about language and examples where it has been used
- Explain why the term has become stigmatized, is inaccurate, or may be inappropriate
- Offer to help provide alternatives and resources if person is comfortable

Don't:

- Accuse the person of being mean/insensitive/discriminatory (e.g. "Why do you dislike people with _____ diagnosis, Tom!")
- Refrain from providing help or resources when asked (e.g. "I shouldn't have to tell you what a better term to use is. You should already know or look it up yourself")
- Gossip or brag to others on the research team about how you told someone their language was stigmatizing and fixed the problem

Addressing Language as a Group

- Utilize assistance such as the staff social worker, someone who works in the field related to the stigmatizing language being used, and professionals on site who may specialize in medical ethics or medical professionalism

- Address the implications of stigmatizing language in the workplace and its potential impact on the quality of research and the experience of subjects in your studies

- Frame creating a positive and healthy research culture as a **team effort**

- Be open to feedback and changing behavior
- Follow-up on language being used and if change is taking place

Activity 3: Language in the Workplace Scenario

Some members of the research team (in meetings and when engaging socially with staff in the research space) have used terms about health or mental health that are either outdated or inappropriate.

Some individuals who do this seem to be unaware that this is an issue and there are others to who have mentioned that what they are saying is "probably not PC, but there are no research subjects around and besides, our subjects use that term all the time!"

Discussion Questions

1. How might someone on this team who is concerned about stigmatizing language being used in the research space address this?
2. What resources might be helpful to this person to go about addressing a workplace culture of using stigmatizing language? Do you know of any resources on your site?
3. What strategies might be helpful for addressing stigmatizing language with someone who doesn't seem to know vs. someone who maybe thinks that it isn't a big deal or that it has not seemed to bother research subjects?

BUMC Resources for Staff and Teams

Employee Assistance Clinician: Beth Milaszewski, LICSW:

Beth can provide individual employees and teams across the hospital with direct support as it relates to stress management in addiction, anxiety, work conflicts, difficult patient encounters, traumatic events and situations, interpersonal skills, difficult team dynamics and more. http://internal.bmc.org/employee-center/employee-wellbeing/employee-assistance-clinician

Grayken Center for Addiction Employer Resource Library:

A set of 25 downloadable tools and resources for employers to address substance use disorders (SUDs), reduce stigma, and create a more inclusive workplace for staff and clients. https://www.bmc.org/addiction/employer-resource-library

Boston Medical Center Ethics Committee:

The Ethics Committee maintains a consultation service to assist in the resolution of ethical dilemmas. The consultation service is comprised of a team of individuals with multidisciplinary expertise. We are available to meet with patients, family members, and staff to provide both guidance and a forum for the discussion of ethical issues that arise in the Boston Medical Center community. http://internal.bmc.org/tools-and-resources/clinical-tools-and-resources-z/clinical-resources/ethics-committee

BUMC Clinical Research Resource Office (CRRO):

The BUMC CRRO both specializes in helping study teams improve the quality of their research design and implementation as well as promotes research participant advocacy. They provide consultations so that research teams can promote best practices and conduct, safe, ethical and non-stigmatizing human research http://www.bumc.bu.edu/crro/

UVMMC & UVM Resources for Staff & Teams

UVMMC Office of Patient & Family Advocacy:

Our patient advocates look into and help resolve patient care-related complaints. We can also answer your questions about confidentiality and patient rights and can get you information about your care. Our advocates are experienced nurses who are here to listen and to help.
https://www.uvmhealth.org/medcenter/Pages/Departments-and-Programs/patient-and-family-advocacy.aspx

The Culture and Work Environment at the UVM Medical Center:

The University of Vermont Medical Center is dedicated to our patients, providing the highest quality care for patients and their families. It is a mission that defines our culture, one of teamwork and collaboration.
https://www.uvmhealth.org/medcenter/Pages/Health-Careers/Culture-and-Work-Environment.aspx

UVM Research Protections Office:

Responsible for the review/oversight programs that support the institution's conduct of safe and ethically sound scientific research https://www.uvm.edu/rpo

UVM Office of Diversity & Inclusion:

Our mission is to build a broadly diverse faculty, student and staff community and to promote a culture that is welcoming and inclusive, and at the forefront of working to achieve health equity in the communities we serve. https://www.med.uvm.edu/diversityinclusion/home

Vermont Conversation Lab:

The mission of the Lab is to understand and promote high quality communication in serious illness. http://www.med.uvm.edu/vermontconversationlab/home

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Thank You!

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