CONSUMER CULTURAL ACTIVATION

Presenters: Lenora Reid-Rose, MBA, Carole Siegel, PhD, Sandra Mitchell

With contributions from:
G. Haugland
J. Hernandez
A. Josephs

Affiliations:
NKI Center of Excellence in Cultural Competency
Coordinated Care Services Inc.
NYU Department of Psychiatry

ACHMA DIG Webinar
11/12/15
Presentation Goals

- Understand the importance in the care process of learning about a consumer’s cultural identity and values.
- Introduce a notion of cultural activation intended to promote consumer’s participation in the therapeutic process.
- Introduce a newly developed tool, Cultural Activation Prompts (CAPs), for use by consumers to help them present salient features of their culture that might influence the care process.
- Introduce a newly developed tool, Cultural Activation Measurement Scale (CAMs) for use by providers to understand consumers’ awareness of the importance of cultural information to their care.
OUTLINE

- Background
  - Basic definitions
  - What is consumer cultural activation?
  - Why is it important?
  - What is it based on?

- Cultural Activation Prompts (CAPs); Cultural Activation Measurement Scale (CAMS)
  - What are these?
  - Illustration of their use
  - Relationship to health literacy and health activation

- Consumer/Peer Specialist’s perspective of cultural activation
INHERENT CULTURE

- Way of life of a group of people that encompasses attitudes, behaviors, beliefs, values, and symbols that are accepted and passed along, by communication and imitation, from one generation to the next
  - Country affiliation
  - Language group
  - Religious group
  - Race/ethnic groups

- Influences the way we think, feel, act, perceive and respond to situations etc.

- Cultural group views are dynamic --influenced by time, place and circumstances
EXPERIENTIAL CULTURE

- Way of life of a group of people that encompasses attitudes, behaviors, beliefs, values, that are learned through living experiences such as
  - Work affiliations
  - e.g., doctors
  - Common experiences
  - e.g., peers
    - LGBT
    - working women
  - Residential experiences
  - e.g., rural folks

- Belonging to an experiential cultural group can change - influenced by time, place and circumstances
Cultural Identity

- Shaped by being part of several ‘cultural groups’ that are important in one’s life.

- Working together, the defining features of these groups make up a **cultural identity**.

- Examples
  - Black professional woman
  - Conservative religious Muslim
  - Recent immigrant from Ecuador who speaks only Quechua
  - Gay person living in the suburbs who works in advertising
CULTURAL INFORMATION CARE GIVERS SHOULD KNOW

- Cultural identity

- What culturally matters when receiving care, recovering and living a valued life in the community
  
  - Worldviews, values and attitudes
  - Cultural strengths
  - Cultural care barriers
  - Cultural supports
IMPORTANCE OF CULTURAL INFORMATION

- Cultural information
  - Improves the *therapeutic encounter*
    - Trust building
  - Enhances likelihood of greater *engagement* and appropriate *retention* in care
  - Allows *care choices* to be made that are more appropriate
  - Allows *recovery plans* to be developed that are better attuned to cultural identity needs
Should conduct cultural assessments
  - Several instruments exist, e.g., APA endorsed DSM V Cultural Formulation Interview

Cultural information should be shared and inform all phases of a treatment encounter

Neither of these events may take place.
**Cultural activation shared concepts**

- **Shared decision making**
  - Sharing cultural information is a form of shared decision making
    - Treatment and recovery planning decisions which are jointly made are enhanced by the personal cultural lens

- **Consumer empowerment**
  - Empowering consumers to represent their cultural values
    - Enhances the direct role consumers can play in making treatment and recovery plans

- **Health activation**
  - Being culturally activated is a part of health activation
    - Health activation is promoted by consumers making known the role cultural views play in their mental health care
PATIENT HEALTH ACTIVATION

- “having skills and confidence that equip patients to become actively engaged in their healthcare.”

  - growing body of evidence showing that patients who are more activated have better health outcomes.

  - Hibbard & Greene, 2013
Health activation is a process

- **Level 1**: Starting to take a role. Individuals do not feel confident enough to play an active role in their own health. They are predisposed to be passive recipients of care.

- **Level 2**: Building knowledge and confidence. Individuals lack confidence and an understanding of their health or recommended health regimen.

- **Level 3**: Taking action. Individuals have the key facts and are beginning to take action but may lack confidence and the skill to support their behaviors.

- **Level 4**: Maintaining behaviors. Individuals have adopted new behaviors but may not be able to maintain them in the face of stress or health crises.

*Increasing Level of Activation*
CONSUMER CULTURAL ACTIVATION

- **Actively participating** in the care process by providing care givers/direct care personnel with a personal **cultural lens** on identity and what matters when receiving care.

- Informing any caregiver seen at any point of time in care delivery of pertinent cultural information that could impact clinical decisions.

- **A portable cultural assessment**
CULTURAL ACTIVATION PROMPTS CAPs: A TOOL TO PROMOTE CULTURAL ACTIVATION

- A list of 15 cues for consumers to use to convey information to caregivers on what culturally matters to them in receiving care.
FOUNDATIONS OF CULTURAL ACTIVATION PROMPTS (CAPs)

- Medical anthropology
- DSM-5 Cultural Formulation Provider Interview
- Consumer input
Medical anthropology

- Medical anthropologist Kleinman’s “Three C’s” of Explanatory Model of Illness
  - Call
  - Cause
  - Course... replaced by expectations of recovery
DSM-5 Cultural Formulation Interview

- Cultural definition of the problem
- Cultural perceptions of cause, context, and support
- Cultural factors affecting self coping
- Past help seeking
- Current help seeking treatment preferences
CONSUMER INPUT TO DEVELOPMENT OF CAPs

- Presentations at Multicultural Advisory Committees in New York State
- Consumer reviews
- Peer specialist reviews
STAGES OF ACTIVATION AND ITS MEASUREMENT

Figure 1: Stages of Consumer Cultural Activation and Cultural Activation Measurement Scale (CAMS) Items

1. I am aware that cultural information can be used to help my care givers plan the best care for me
2. I know the cultural groups I identify with
3. I know who from my cultural groups can support me while I receive care
4. I know how persons from my cultural groups can affect my ability to stay in care
5. I am confident that I can tell care givers about the strengths and supports provided to me by persons from my cultural groups
6. I am confident that I can tell care givers about how persons from my cultural groups could affect my receiving care
7. I am confident that I can remind care givers of my cultural information whenever I think it will help making decisions about my care
8. I am confident that I can tell my care givers about changes in my cultural information if and when it is appropriate
Cultural Activation Prompts
CULTURAL ACTIVATION PROMPTS (CAPs) FOR CONSUMERS: PROMPTS TO START A CULTURAL CONVERSATION WITH YOUR CARE GIVERS.

Tell them:

- What you would like to be called
- The kind of person you would like to receive care from. *Even though the person you may be seeing for your care is not your first choice, it is still good to talk about this.*
- The different cultural groups you identify with because you share some of their important values and world views... *this is your cultural identity*
- Any negative or traumatic experiences you have had related to your cultural identity
- The names given by persons in the groups you culturally identify with for why you are seeking care, *even the ones that may be hurtful*
- What persons from the groups you culturally identify with think may be the cause(s) of your seeking care
- Why you think you need care
- What attitudes persons from the groups you culturally identify with have about your seeking care
- What supports might be given to you from persons from the groups you culturally identify with while you are receiving care
- What stresses might be placed on you by persons from the groups you culturally identify with when you are receiving care
- Who from the groups you culturally identify with might help you while you are in care
- Kinds of different care or alternative practices that you have had that have been helpful
- Care that you have had that was not helpful
- Things you like to do with groups you culturally identify with where you live, worship, shop, socialize, etc.
- What indicates to persons from the groups you culturally identify with that you are in recovery
CAPs

- Cultural Identity
  - Combinations of race, ethnicity, country you or your family came from, language you like to speak, how long you are in the US, community you live in, gender, educational level, income, occupational status, gender, sexuality, political and faith and religious affiliation, etc....

- Cultural view of mental health challenges
  - Call, cause, stigma, trauma

- Cultural supports and stressors
  - From cultural network
  - From providers
    - Treatment preferences

- Recovery
  - Desirable community outcomes
  - Desirable community supports
CAPs: Cultural Identity

- Tell your care giver cultural identifying items that are most important to you and might help him/her get to know you better.
  - Combinations of race, ethnicity, country you or your family came from, language you like to speak, how long you are in the US, community you live in, income, occupation, gender, sexual orientation, faith or religion, etc....
What is your cultural identity?

- 2nd generation Latino, engineer
- Black, female, professional
- Conservative religious Muslim
- Immigrant from Russia
- Asian, gay, suburbanite, academic

Lenora’s response

1. I identify myself as Black, not African American.
2. I identify myself as Jamaican American.
3. I identify myself as a mother.
How you would like to be called?

- first name OK
- señora
- name you have adopted or feel more comfortable with

**Lenora’s Response**

1. I would like to be called Lenora.
2. I would like to be called Mrs. Reid-Rose.
3. I would love to be called Lenny. That’s what my friends call me.
What do you call the reason for why you are seeking care?

- nerviosa
- nervous breakdown

*Lenora’s Response*

1. “crazy”
What people from your cultural groups think might be the causes of needing to seek care

- bad Karma
- physical problem
- sinner

*Lenora’s Response*
1. Hanging around with the wrong crowd
2. Not going to church
While planning for course of recovery, things you want to happen.

- Return to work
- Get off meds
- Attend social functions
- Greater participation in family life

_Lenora’s Response_

1. I want to party with my friends
2. I want to go back to singing on the church choir
Any negative or traumatic experiences you have had because of your cultural identity

- Racism
- Stigma
- Exclusion
- Name calling

**Lenora’s Response**

1. I have been discriminated against at work.
2. I have been passed over for the president of the Snow Club.
3. I have experienced racism.
4. I have been called ugly names.
Kinds of alternative treatment, advice or healing that you have used that were helpful

- herbs
- Botanica
- spiritual counseling

**Lenora’s Response**

1. Drinking *moringa* tea
2. Tying “sour sop leaf on my head
3. Going to church and speaking with my Minister
4. Massage
5. Acupuncture
Care that you have had that is **not helpful**; attitudes toward care

medications will not help.....only prayer will heal

**Lenora’s Response**

1. God knows best; he does not give me more than I can bear; he will take care of me; pray harder
2. Those people want to work experiments on me
Kind of person you would feel good about getting care from

- female (for female)
- religious Jew
- person who speaks my language
- Older person

**Lenora’s Response**

1. Mature black female
2. Someone from one of the Caribbean islands
3. Someone who understands the Jamaican dialect and can pick up the nuances in my accent
Who from your cultural group might help you while you are in care?

**Lenora’s response:**
1. My cousin who lives in Jamaica
2. My best friend in Atlanta
3. My daughter
4. My minister
CAPs: Supports/Stressors

- **What supports** might your cultural group provide for you knowing you have sought care?
  
  family/kin accompany you to clinic
  prepare meals

- **Stresses** you or people from any of the groups you identify with feel about your seeking care
  
  viewed as weak
  take away from family responsibilities

- **What might help you cope** with your situation?
  
  religion and church going
  participation in community groups

- **Your views or values and that** of your cultural group that might **interfere with** you getting better?
  
  felt group discrimination
  importance of work
  religious and spiritual beliefs
HOW CAPS COULD BE USED

- Posters in program rooms.
- Hip pocket/purse laminated card/Youtube/APP.
- With help of peer specialists:
  - Motivate and encourage consumers on the value of sharing this information with providers
  - Use cultural information in conversations with consumers
  - Use prompts as a way to begin conversations to build trusting relationships
- Create a cultural card. Consumers and their family members can be encouraged to create a “cultural card” prior to seeing their provider.
**Sample Card - Lenora**

<table>
<thead>
<tr>
<th>CUE</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I want to be called .......</td>
<td>1. Lenora</td>
</tr>
<tr>
<td>2. I want to be identified as ..........</td>
<td>2. Black, Jamaican American</td>
</tr>
<tr>
<td>3. Trauma I have experienced because of my cultural identity</td>
<td>3. Discriminated at work; racism in social settings and called ugly names</td>
</tr>
<tr>
<td>4. Individuals from my cultural group that know of my condition and will help...</td>
<td>4. My daughter will help; however I will talk to my cousin and best friend</td>
</tr>
<tr>
<td>5. The name they give to why I am seeking care</td>
<td>5. “Crazy”</td>
</tr>
<tr>
<td>6. Things that have helped me</td>
<td>6. Drinking moringa tea and eating the seeds; talking to my minister</td>
</tr>
</tbody>
</table>
In Conclusion: Activation Triad

Health Literacy <-> Cultural Activation

Health Activation