My Life, My Healthcare: The ICAN Discussion Aid

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Objectives

1. Understand different conceptual foundations for discussing problems and issues in MCC.
2. Learn how to use the ICAN Discussion Aid.
3. Distinguish conversations using ICAN from conversations in current practice.
Joan

Dialysis

ESRD

Diabetes

Medications
“Non-Compliant”
Activity
1. Pair up. Decide which person will play “patient” and the other “clinician.”

2. Patients – take time to read Joan’s story.

3. Clinicians, when the patient is ready, begin the conversation with Joan by asking “What can I do for you today?”
Discuss
Evidence synthesis

Initial prototype

Designers
Study team
Patient advisory groups
Clinicians
Stakeholders

Modified prototype

Final Communication Tool

Evaluation (trial)

Field testing

Observation clinical encounters
Disease-specific guidelines and quality targets
Multiple treatments | Monitoring tests
Limited care prioritization
Poor care coordination

Life

Workload

Capacity

Scarcity

Burden of treatment
access
use
self-care

Outcomes

Burden of illness

Shippee N et al JCE 2012
The Burden of Treatment

- Emotional Problems
- Role and activity limitations
- Financial challenges
- Confusion about medical information
- Systemic problems

Eton et al. 2012
• ICAN Design research
  • Looking at how Patients and Clinicians discuss chronic illness
  • 15 observations of clinical encounters
  • 9 prototypes tried out in 59 encounters
**PATIENT HEALTH QUESTIONNAIRE (PHQ-9)**

**NAME:**

Over the *last 2 weeks*, how often have you been bothered by any of the following problems? (use “✓” to indicate your answer)

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

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resound

- origin ME: from re-
- resonder or L. resonare ‘son.’
- derivatives resounding

resource

- origin C17: from OFr.
- as n.) of OFr. resourc}
- derivatives resource

or supply of materials or
adopted in adverse cir-
sonal attributes and can
verse circumstances.

resources.

- origin ME: from re-
- resonder or L. resonare ‘son.’
- derivatives resounding

booming, or echoing
much talked of. [as a

takable: a resounding standing] emphatic;

- derives from resound

- adj. formal or archaic

take to heal or dispel some-

adj. formal or archaic
decide (body) take
o something seen at
when seen more

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when seen more
WHAT MAKES YOU FAMOUS?

HEALTH?

PROBLEM SOLVING

SOCIAL

PERSONAL

EMOTIONAL

FINANCIAL

ENVIRONMENTAL

RESULTS

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WHAT MAKES YOU FAMOUS?

Being a mom and wife

POIY

HEALTH?

Standing for prolonged period of time difficult

Autonomic dysfunction

Tired, lightheaded, can't complete 'normal' day to day activities

Hides from situations not well known

PROBLEM SOLVING

Have to pretend being ok/well

Attending activities with children

Annoying, taxing

Headaches

Fatigue

RESULTS

Household activities

EXERCISE

Environmental

Physical

FINANCIAL

Improved with better insurance (ACCESS)

PERSONAL

Weight shaky son

SOCIAL

EMOTIONAL

IMPROVEMENTS

ENQUIRING
I'm concerned about

- My Home or Neighborhood
- Finances
- How I'm Feeling
- Family Demands
- Getting Around
- Stigma
- Understanding my Situation
- My Social Life
- Eating Well
- Healthcare
- Having Time

Obstacles to Addressing

Costs or Consequences
<table>
<thead>
<tr>
<th>I’m concerned about</th>
<th>Does this have costs or consequences?</th>
<th>Are there are obstacles to addressing this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Energy Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having Time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Demands</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finances</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How I’m Feeling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My Home or Neighborhood</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain or Rest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting Around</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stigma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthcare</td>
<td>Diabetes</td>
<td>Kidneys can fail (strokes in past)</td>
</tr>
<tr>
<td>My Social Life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating Well</td>
<td></td>
<td>eating better</td>
</tr>
<tr>
<td>Understanding my Situation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Areas in your Life

- Family and Friends
- Comfort and Rest
- Finances
- Meaning and Belonging
- Healthcare
- Being Active
- Relaxation & Fun
- I Experience Burden
- I Experience Satisfaction
- Work
- Home and Neighborhood
- Emotional Life
I find these areas of my life a source of...

Family and Friends

Work

Comfort and Rest

Home and Neighborhood

Finances

Emotional Life

Being Active

Healthcare

Free time, Relaxation, Fun

Meaning and Belonging

Eating Well
Diabetes

Medical Problems
- chronic concerns

Healthcare
- treatments
- tests
- procedures

I Experience Burden
- Being Active
- Relaxation & Fun

I Experience Satisfaction
<table>
<thead>
<tr>
<th>Areas</th>
<th>Satisfaction</th>
<th>Burden</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family and Friends</td>
<td>✔️</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td>✔️</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Comfort and Rest</td>
<td>✔️</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
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<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Finances</td>
<td>✔️</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Emotional Life</td>
<td>✔️</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Being Active</td>
<td>✔️</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>My Senses and Memory</td>
<td>✔️</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Free time, Relaxation, Fun</td>
<td>✔️</td>
<td>✔️</td>
<td></td>
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<tr>
<td>Meaning and Belonging</td>
<td>✔️</td>
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<tr>
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<td>✔️</td>
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Are the things that we're doing a help, a burden, or both?

- Zoloft
- Trazadone
- Suggested stop of marijuana coming into see us
Are these areas of your life a source of satisfaction, burden, or both?

- My Family and Friends
- My Work
- My House & Neighborhood
- My Finances
- Free time, Relaxation, Fun
- Faith or Personal Meaning
- Being Active
- My Rest and Comfort
- My Emotional Life
- My Senses and Memory
- Eating Well

What are the things that your doctors or clinic have asked you to do to care for your health?

For example:
- Come in for appointments
- Take aspirin

Do you feel that they are a help, a burden, or both?

- Track carb intake
- Get rest
- Eat 6 meals a day

Comments
My Life My Healthcare

How does your healthcare fit with your life?

This discussion aid will help you and your clinician talk about how your healthcare fits with your life.
Are these areas of your life a source of **satisfaction**, **burden**, or **both**?

<table>
<thead>
<tr>
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<tr>
<td>My family and friends</td>
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<td>My work</td>
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<td>Free time, relaxation, fun</td>
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<tr>
<td>Faith or personal meaning</td>
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<tr>
<td>Where I live</td>
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<tr>
<td>Getting out and transportation</td>
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Your Life  Your Healthcare

- What are you doing when you’re not sitting here with me?
- Where do you find the most joy in your life?
- What’s on your mind today?

These questions can help shift discussion towards the broader life of your patient. Use as many of them as you wish.
Care of people living with multiple chronic conditions is not only complex, it is ambiguous.
Two Communicative Strategies

- Remove ambiguity by making definite
  - Define, Assess, Interpret, Diagnose
Two Communicative Strategies

• Remove ambiguity by making definite
  • Define, Assess, Interpret, Diagnose

• Make ambiguity productive for the people involved
  • Invention, meaning making
Capacity Domains

- **Personal**
  - resilience
  - self-efficacy
  - literacy

- **Emotional**
  - depression
  - anxiety

- **Physical**
  - pain
  - fatigue

- **Financial**
  - healthcare expenses
  - other scarcity

- **Social**
  - instrumental support
  - friends & family for socializing

- **Environmental**
  - healthcare coordination
  - home and neighborhood
Fig. 2 Taxonomy of the burden of treatment

- Factors that exacerbate the burden of treatment
- Healthcare tasks
- Consequences of healthcare tasks imposed on patients in their daily lives

Tran et al. BMC Medicine (2015)
Life | Healthcare
I love shoveling snow
Activity
Your Life Your Healthcare

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</table>
1. Fill out an ICAN. You may fill it as yourself, as a pretend patient, or as Joan.

2. Get in your pairs again.

3. Decide who will play patient first.
4. Clinicians – begin the visit by using one or more of the 3 questions on the clinician card.

5. Ask the patient what stands out to them from what they have filled on the patient sheet.

6. After about 5 minutes, you will be asked to switch roles – if you were the patient, you will now be the clinician.
Meaningful Conversations
More about MDM:
http://minimallydisruptivemedicine.org

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