

Shared Decision-Making: Measurement and Practice

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and Community Health**



New England (HHS Region 1)

MHTTC

Mental Health Technology Transfer Center Network

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The MHTTC Network uses affirming, respectful and recovery-oriented language in all activities. That language is:

STRENGTHS-BASED
AND HOPEFUL

INCLUSIVE AND
ACCEPTING OF
DIVERSE CULTURES,
GENDERS,
PERSPECTIVES,
AND EXPERIENCES

HEALING-CENTERED AND
TRAUMA-RESPONSIVE

INVITING TO INDIVIDUALS
PARTICIPATING IN THEIR
OWN JOURNEYS

PERSON-FIRST AND
FREE OF LABELS

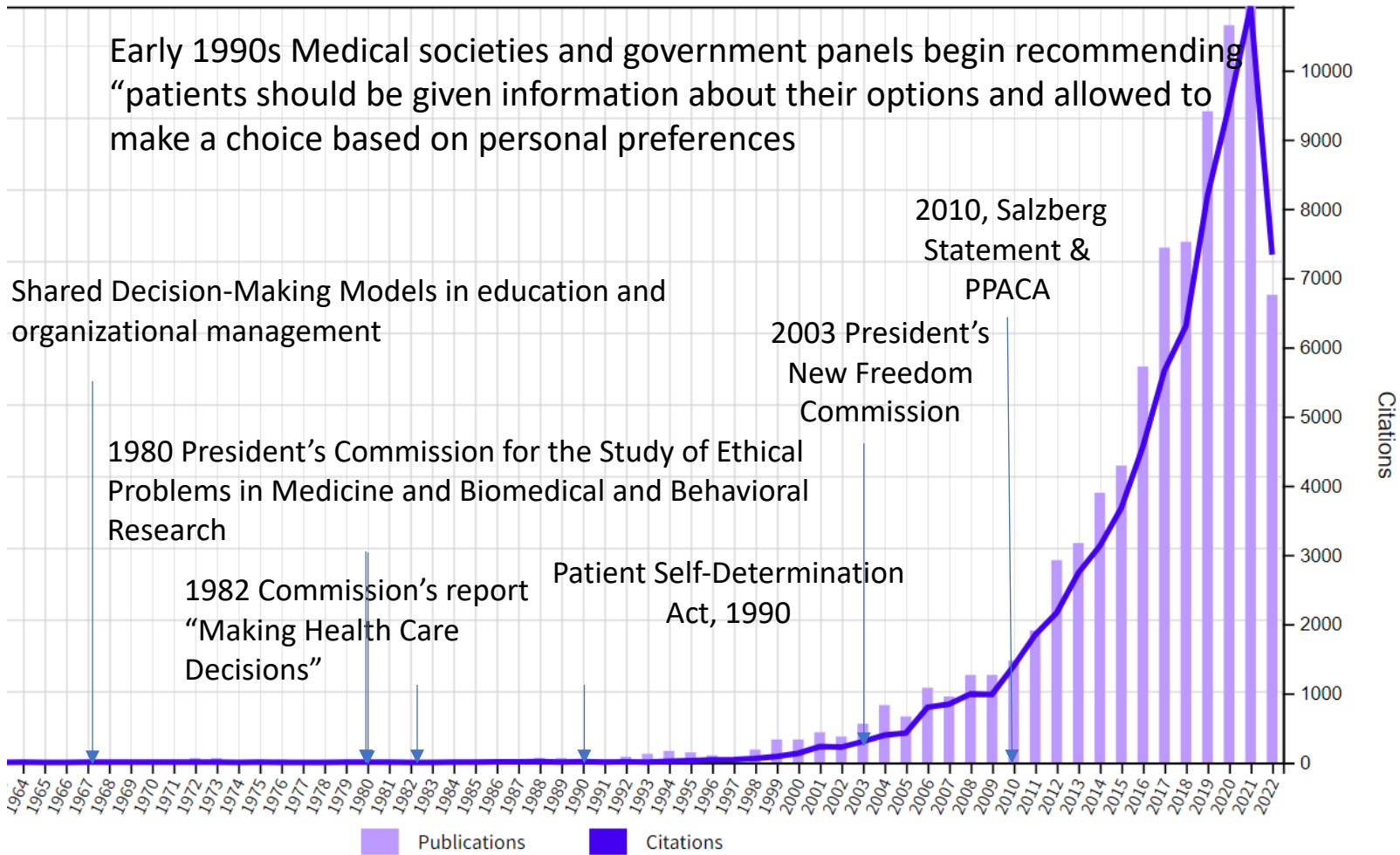
NON-JUDGMENTAL AND
AVOIDING ASSUMPTIONS

RESPECTFUL, CLEAR
AND UNDERSTANDABLE

CONSISTENT WITH
OUR ACTIONS,
POLICIES, AND PRODUCTS



Early 1990s Medical societies and government panels begin recommending “patients should be given information about their options and allowed to make a choice based on personal preferences



Person- centered healthcare

- **services and treatments that are “consumer and family centered [and] geared to give consumers real and meaningful choices”**
- *President’s New Freedom Commission Report, 2003*
- “care that is respectful of and responsive to individual patient preferences, needs, and values, and ensur[es] that patient values guide all clinical decisions.”
- -Institute of Medicine, 2001
- “Is inclusive of an individual’s preferences, autonomy and needs, focusing on outcomes that people notice and care about such as survival, function, symptoms, and health-related quality of life”
- - Patient Centered Outcomes Research Institute (PCORI), 2010

Research shows that...

Individual studies suggest that patient care based on, informed by, and tailored to patient preferences is associated with..

- greater engagement in treatment,
- improved therapeutic alliance,
- increased patient satisfaction, and
- improved outcomes of care

(Andersen & Urban, 1999; ay a Pinikahana, 2007; Donovan, 1995; Greenfield, Kaplan, & Ware, 1985; Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Hibbard & Greene, 2013; Kaplan, Greenfield, & Ware Jr, 1989; LeBlanc, Kenny, O'Connor, & Legare, 2009; Stacey, Carley, Ballantyne, Skrutkowski, & Whynot, 2014).

Shared Decision Making Models

- A recent review identified 40 models of SDM in the literature (Bomhof-Roordink, Gartner, Stiggelbout, & Pieterse, 2019)
- Models included elements of...
 - Describing treatment options (88%) (benefits, risks, feasibility of options, listing options, providing evidence)
 - making a decision (75%) (documenting decision, patient retains ultimate authority over decision, revisiting decision)
 - patient preferences(65%) (concerns, goals of care, values)
 - Tailoring information (65%) (ascertain preferred information, checking/clarifying, using clear language)
 - deliberation or negotiation (58%)
 - 53% had elements of learning about the patient (checking/clarifying/understanding)

The SHARE Approach

5 Essential Steps of Shared Decision Making



1. TEAM TALK

Work together, describe choices, offer support, and ask about goals

"Let's work as a team to make a decision that best suits you"

ACTIVE LISTENING

Paying close attention and responding accurately

2. OPTION TALK

Discuss alternatives using risk communication principles

"Let's compare the possible options"

3. DECISION TALK

Get to informed preferences, make preference-based decisions

"Tell me what matters most to you for this decision"

DELIBERATION

Thinking carefully about options when facing a decision

Source: BMJ 2017;359:j4891. DOI: 10.1136/bmj.j4891.

Informed
Decision Making

Shared Decision
Making

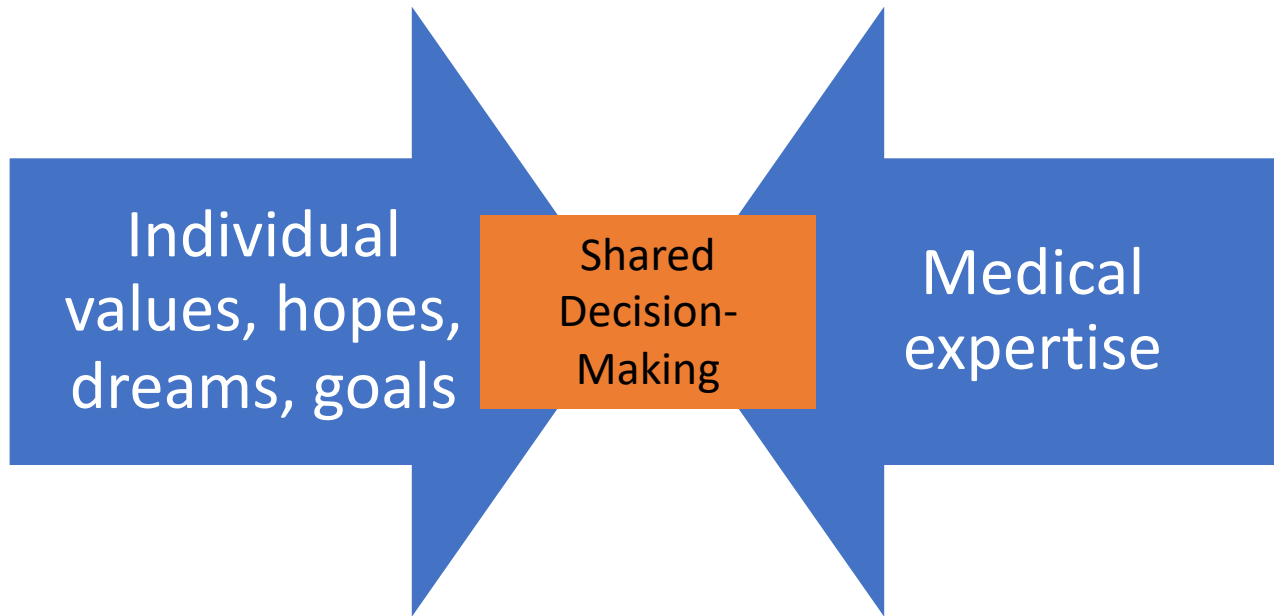
Paternalism



Involving individuals in decisions about care

- Is NOT just asking people what they want
- Involves providing people with accurate information about the available options and engaging with them in a process of weighing risks and benefits associated with various options, then having them decide what course of action is most consistent with their preferences, goals, and values.


A values-centered framework



*Development of a Shared
Decision-Making Tool for
Persons with Chronic Illness*


Background

- Current models of shared-decision making in medicine emphasize the collaborative relationship between a practitioner and patient in making informed treatment decisions.
- Central to these models is a presumption that people have enough information to identify and choose treatment that is consistent with their values, goals, and preferred states of health.
- But the range of decisions that can be, or should be, made within the context of a shared decision-making process is fairly restricted, limited to predetermined treatment options.
- While important, these are not necessarily the personal decisions most meaningful to people with chronic illnesses.



Objectives of the study:

to improve clinical practice and enhance services through the development of a supported decision-making tool that can help people with chronic illnesses:

- a) identify and communicate their preferences about treatment and health outcomes, and
 - b) make healthcare decisions that are consistent with their preferences, goals, and values.
- 

Phases of Research

42 qualitative interviews were conducted with individuals living with a chronic physical and/or mental illness for various lengths of time (<3 years or 5+ years, n = 22), family members (n = 10), and physicians (n= 10)

Statement generation groups were held with 34 persons living with a chronic physical or mental illness to solicit responses to 2 primary questions:

What are the areas of your life that are the most important to you, that you value, that you hope for and that give you meaning?

What does a doctor need to know about you in order to provide high quality care?

Online Practitioner Survey to assess provider views (n = 60) of what they needed to know about patients in order to provide high quality care, definitions of patient-centered medicine, what was needed in healthcare system in order to promote patient-centered medicine

Qualitative Interviews

- 40 qualitative interviews were conducted
 - 10 interviews with individuals who have recently been diagnosed with a chronic physical or mental illness (<3 years)
 - 10 interviews with individuals who have been living with a chronic physical or mental illness (5+ years)
 - 10 interviews with family members who have a close loved one living with a chronic physical or mental illness
 - 10 with physicians who specialize in treatment of chronic physical or mental illness

Patient's said

- “He asked me a couple of questions, wrote something down, put me on some medication and pushed me out the door.”
- “I think it’s really, really important that I control what goes on with me. Don’t nobody know my body like me. I make ninety-five percent of the decisions. My doctors are just there to listen and to tell me what my options are.”
- “Every day I'm fine, I can do regular things that everybody else does. But at night when I have to prepare myself to take this medication it's my constant daily reminder that you have a chronic disease with no cure.”
- “I have basic state insurance and I’m not getting consistency from doctors. I’ll have a great doctor but they’ll be there and then I’ll have another one. Nothing is consistent. That drives me crazy.”
- “At first I went through a period of not trying to accept it. The more and more I would refuse to accept it the more and more I was hurting myself so I had to make a decision to do something about it. I just couldn't act as though it don't exist because I was hurting. not accepting it caused it to be worse.”

Physicians said...

- “Giving people the burden of a choice when they are not equipped or don't want it, it's not necessarily in their best interest.”
- “I think it's important to notice that I have needs in the encounter in addition to the patient's needs. Legal , obligations to my training program , obligations to my own sense of safety sending somewhere out into the community.”
- “I consider them to be an authority on their daily life and me to be an authority on medical concerns. In some ways, I offer myself as a consultant in that capacity, not an authority like the boss of them but an authority that is available to them.”
- “I used to be attached to my [treatment] plans because they were...evident based and bound to be effective. [But I've] realized that...a mediocre plan that's carried out is much better than the perfect plan that's ignored.”
- “It would be insane to try to force one option over another given you're not curing them.”
- “I still want the treatment plan to reflect what they would want, but not completely, if that's going to be detrimental to them. I know that I'm making a paternalistic decision here, but I think that's acceptable to a certain extent, because they are very impaired, and unable to make those decisions for themselves.”
- “If she wanted a certain brand of dishwashing soap, she was entitled to it...that was the way she felt about Chantix”

Phase 2 : Statement Generation Groups

4 statement generations groups were held

participants were persons living with a chronic physical or mental illness

Groups were facilitated by a member of the core research team and a member of the advisory board

Two main questions were asked:



Question One

- “We are developing a tool that will help patients and their doctors make treatment decisions that reflect the hopes, values, and goals of the patient. The purpose of this focus group is to help us understand the areas of your life that are the most important to you, that you value, that you hope for and that give you meaning. **SO, WHAT ARE THE MOST IMPORANT THINGS TO YOU?”**

Question Two

- **"What does your doctor need to know about you & your life in order to provide you with good care"**



Concept Mapping Groups

Persons living with a chronic illness were invited to participate in concept mapping groups (some of these folks also participated in the focus groups)

A total of 59 people sorted the 100 items into piles of similarity.

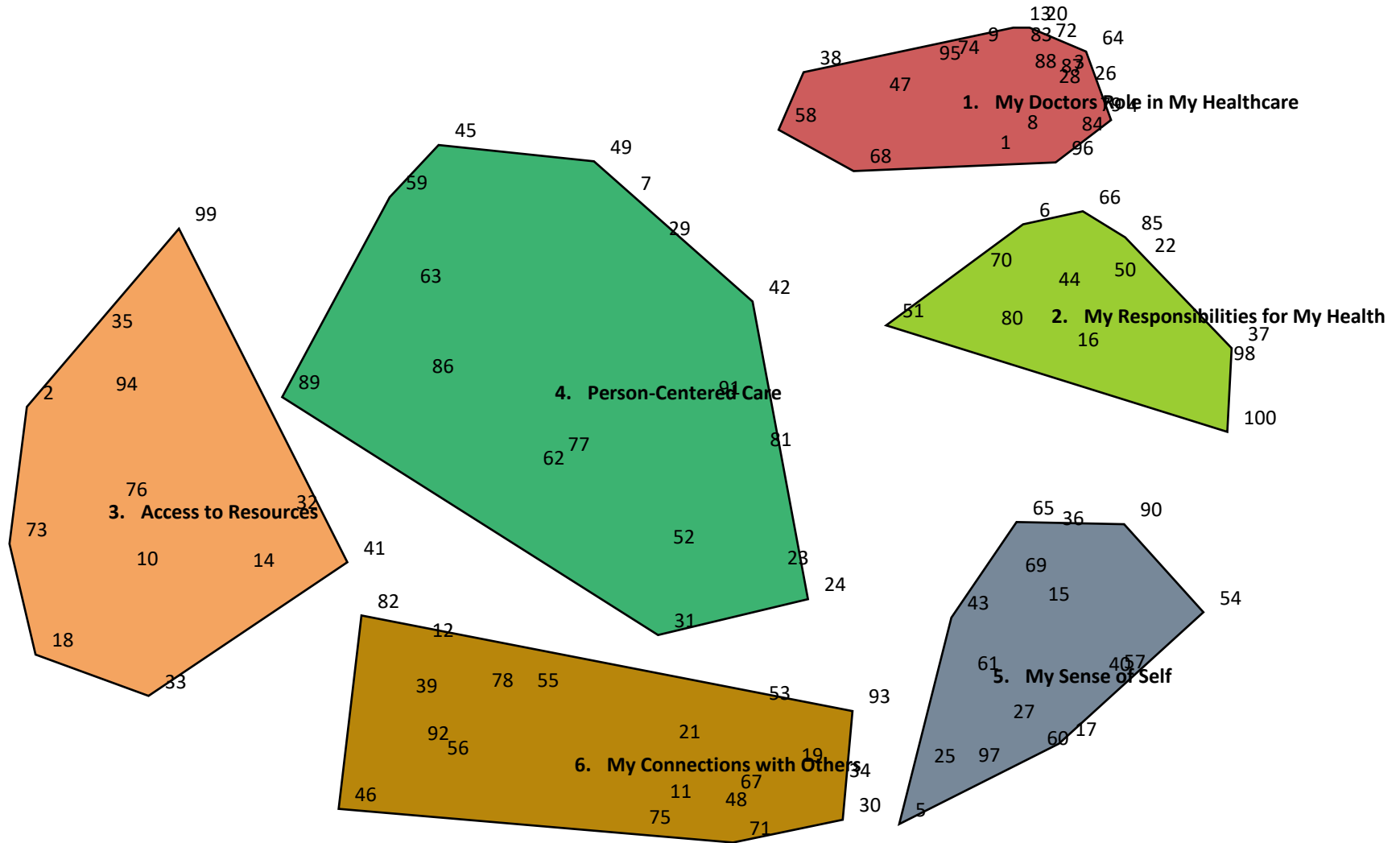
The rules were:

You can't have 100 piles

You can't have only 1 pile

Piles ranged from 2-35

Concept Map



My Healthcare Map



What do you most want from your doctor today?

Rank only the top three.

(Use the examples given or write in your own values, then rank 1,2,3)

- To obtain medication that works for me
- To be treated as a whole person
- To be informed of all options for treatment
- To know his/her opinion about the one best treatment
- To share his/her knowledge and expertise
- To receive an accurate diagnosis
- To tell me the truth even if he/she is uncertain
- To communicate with my other healthcare professionals
- To work with me as a partner
- For all the staff to be kind to me
- Not to rush me
- To ask me who I want to be involved in my care
- To respect my time
- To ask me what I'm most worried about

**My Doctors'
Role in My
Healthcare**

What do you need to do or try to do to take care of yourself?

(Use the examples given or write in your own, then rank 1,2,3)

- ___ Understand my illness
- ___ Keep my symptoms under control
- ___ Ask questions
- ___ Take my medication as prescribed
- ___ Accept my illness
- ___ Manage my stress
- ___ Set my own goals for treatment
- ___ Deal with how my illness affects my emotions
- ___ Understand what my illness means for me

My
Responsibilities
for My Health

My Doctors'
Role in My
Healthcare

What are three aspects about yourself that are important to you?
(Use the examples given or write in your own values, then rank 1,2,3)

- ___ taking care of myself
- ___ being trusted by others
- ___ being independent
- ___ being able to express my worries, fears, and concerns
- ___ my physical appearance
- ___ fulfilling my responsibilities
- ___ having a good relationship with my kids/family
- ___ feeling hopeful about the future
- ___ my strength and determination



What else is on your mind today?

(Use the examples given or write in your own values, then rank 1,2,3)

My
Responsibilities
for My Health

My Virtues,
Values, and
Core Beliefs

My
Connections
with Others

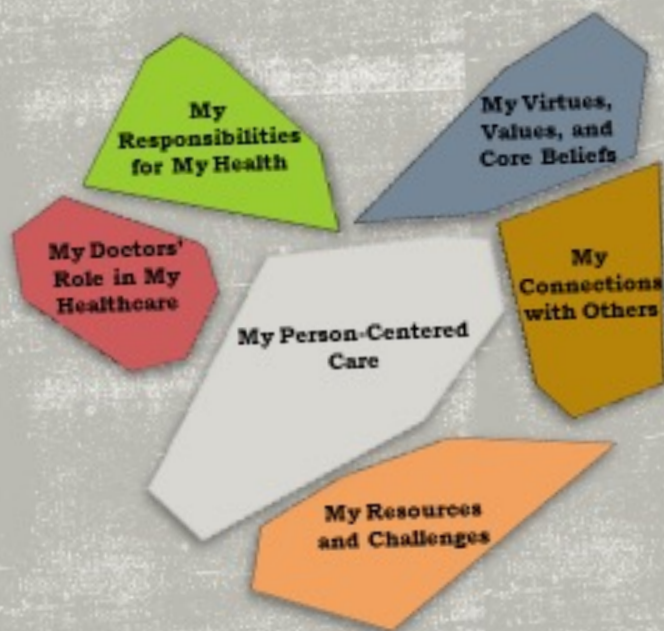
My Resources
and Challenges

- ___ housing
- ___ my financial resources and responsibilities
- ___ my hobbies and interests
- ___ my culture and spirituality
- ___ transportation issues
- ___ my education
- ___ work

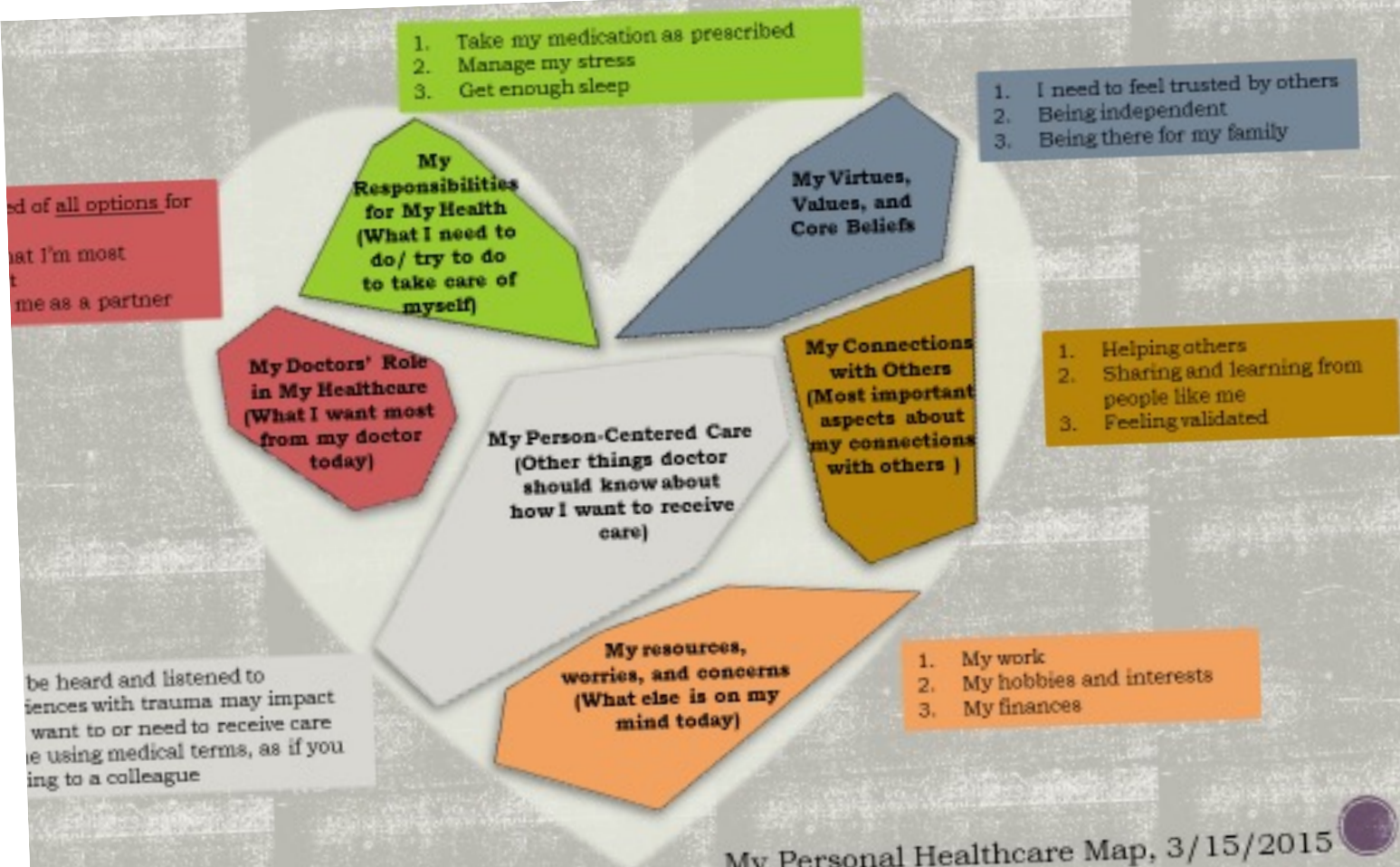


What else should your doctor know about how you want to receive care or treatment?

(Use the examples given or write in your own values, then rank 1,2,3)



- It is important to have a doctor who talks to me in a way that I understand
- I need to know what my rights are
- I need to be able to advocate for myself
- I need to be heard and listened to
- I have concerns about my weight
- Do not judge me
- I need to have someone who can advocate for me
- My experiences with trauma may impact the way I want to or need to receive care
- Accommodations that I need (flexibility at work, interpreter, handicap ramp, etc.)



My Personal Healthcare Map, 3/15/2015

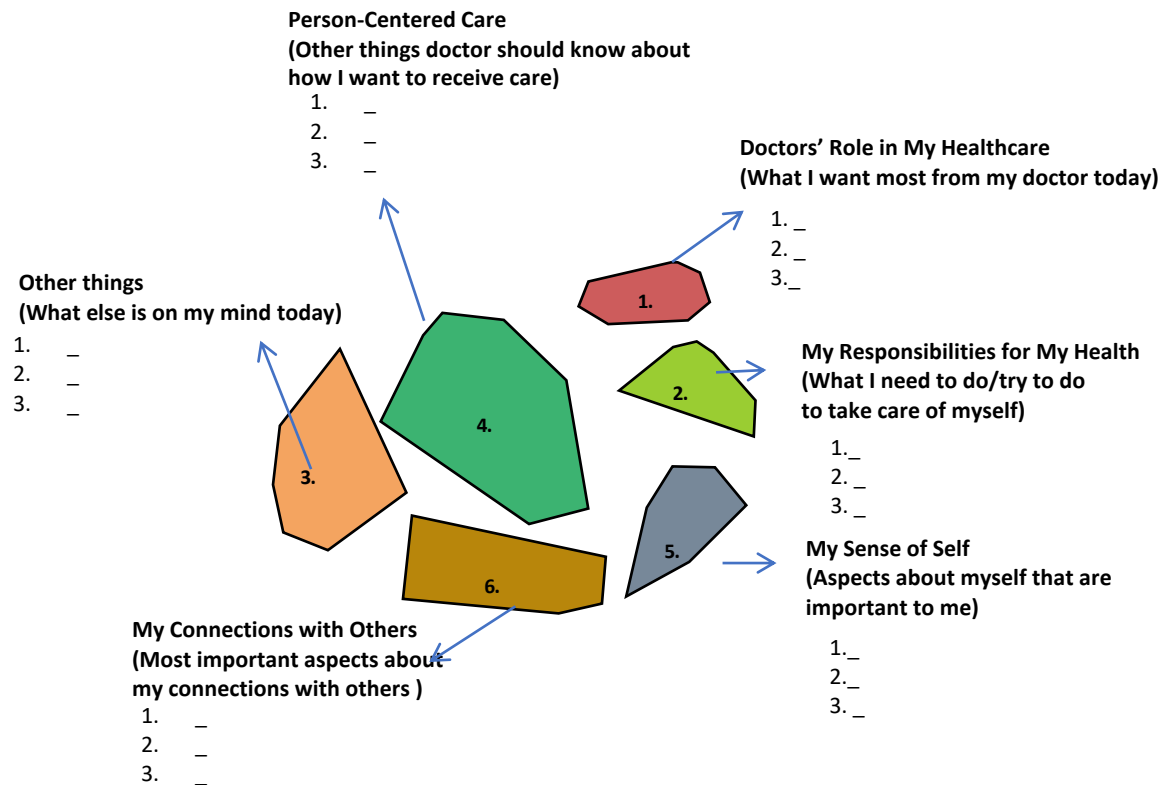


“there’s definite need for these types of programs about how to communicate with your healthcare providers and importance of participating in their treatment.”
Physician

Participants said..

“The tool helped me feel like I belonged and had a say...” and “for the first time, I felt like the appointment was 'mine'”.

“It put the ball in my court”



“going through all the possibilities made me think about what I really wanted what to get out of my appointment. I know doctors cram in appointments and get double booked...so [they] are rushed. [This helped me make the] best possible use of my time. I think that it’s great.”

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