Having better conversations about goals of care with patients who have serious illness

John J. You, MD MSc
Dev Jayaraman, MD MPH

MUHC Medical Grand Rounds
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Faculty/Presenter Disclosure

• Relationships with commercial interests:
  – None

• Research funding:
  – Canadian Frailty Network
  – Canadian Institutes of Health Research
  – Heart and Stroke Foundation
  – Ontario AFP Innovation Fund
Objectives

• To review current gaps in communication about goals of care with patients who have serious illness

• To learn about the Serious Illness Care Program, a framework to support clinicians in having more effective conversations about goals of care
Questions

1) It is important to invite patients to have a discussion about their prognosis when they are facing serious, life-limiting illness
TRUE or FALSE

2) A goals-of-care conversation should focus on what procedures a patient does or does not want during serious illness
TRUE or FALSE
Take home points

• Goals-of-care discussions are often too little, too late, and not great

• Patients who have serious illness often receive care that is not consistent with their values and goals

• The Serious Illness Conversation Guide offers a potential solution
Trajectories of dying

Defining priorities for improving end-of-life care in Canada

Daren K. Heyland MD MSc, Deborah J. Cook MD MSc, Graeme M. Rocker DM MHSc, Peter M. Dodek MD MHSc, Demetrios J. Kutsogiannis MD MHS, Yoanna Skrobik MD, Xuran Jiang MD MSc, Andrew G. Day MSc, S. Robin Cohen PhD, for the Canadian Researchers at the End of Life Network (CARENET)

Better communication and decision-making

- Consistent information from care team
- Having things explained in a way they can understand

Heyland DK et al. CMAJ. 2010.
A person's values, wishes, beliefs and goals for their care

Info guides future decision-making

Info directly informs decision-making

Future Care

Advance Care Planning Conversations

Goals of Care Discussion

Decision-Making or Consent Discussion

Current Care

Treatment Decisions to be made

Figure: Relationship between three discussions that contribute to informed consent
The prevalence of medical error related to end-of-life communication in Canadian hospitals: results of a multicentre observational study

Daren K Heyland,¹ Roy Ilan,² Xuran Jiang,³ John J You,⁴ Peter Dodek⁵
## Study participants

<table>
<thead>
<tr>
<th></th>
<th>Patients N=808</th>
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<tbody>
<tr>
<td>Age, years, mean (SD)</td>
<td>80 (9.4)</td>
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<tr>
<td>Female, n (%)</td>
<td>455 (56.3)</td>
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<tr>
<td>Caucasian, n (%)</td>
<td>765 (94.7)</td>
</tr>
<tr>
<td>Charlson Comorbidity Index, mean (SD)</td>
<td>2.8 (2.6)</td>
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<td>Frail, n (%)</td>
<td>280 (34.7)</td>
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<td>Health Literacy (REALM-R score), mean (SD)</td>
<td>7.3 (1.5)</td>
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<td>Inclusion criteria, n (%)</td>
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<tr>
<td>Age 55+ with advanced chronic disease (e.g. COPD)</td>
<td>319 (39.5)</td>
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<tr>
<td>Age 80+</td>
<td>477 (59.0)</td>
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<tr>
<td>Would not be surprised if died &lt; 6 months</td>
<td>12 (1.5)</td>
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Are medical errors common?

All possible treatments including CPR
ICU admission, No CPR
Full medical treatment, No CPR
Comfort oriented treatment, No CPR

<table>
<thead>
<tr>
<th>Preferences*</th>
<th>Documented goals*</th>
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Crude agreement  = 35%
1 in 3 patients experience a medical error

Medical error rate = 36.4%

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1 in 3 patients experience a medical error

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Medical error rate = 36.4%
Potential under-treatment = 1.6%
Potential over-treatment = 34.8%
1 in 3 patients experience a medical error

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Medical error rate = 36.4%
Potential under-treatment = 1.6%
Potential over-treatment = 34.8%
- Asked about prior discussions or written documents
- Offered a time to meet to discuss goals of care
- Provided information to review about ACP prior to discussions
- Discussed prognosis
- Asked what is important to patient as they consider health care decisions
- Provided information about outcomes, risks, benefits of LST
- Provided information about outcomes, risks, benefits of comfort care
- Helped access legal documents to document ACP
- Asked the respondent if they had additional questions about goals of care
- Gave an opportunity for the respondent to express fears or concerns
- Asked about preferences for care in event of life-threatening illness

Common barriers to goals of care (GoC) discussions ...

- Clinicians uncomfortable initiating GoC discussions
- Emotional barriers that impede patients from engaging in GoC discussions
- Focus on procedures, not values, leads to lack of patient engagement in GoC discussion
- Physicians fail to disclose prognosis
- Poor clinician communication leads to inadequate understanding of prognosis by patients
Atul Gawande

Being Mortal

Medicine and What Matters in the End
Serious Illness Care

Helping seriously ill patients choose care that’s aligned with their values and goals

The Serious Illness Care program facilitates appropriate conversations between clinicians, seriously ill patients and their families. Drawn from best practices in palliative care, the intervention provides guidance for clinicians to initiate these difficult
“I’m hoping we can talk about where things are with your illness and where they might be going — is this okay?”

“What is your understanding now of where you are with your illness?”

“How much information about what is likely to be ahead with your illness would you like from me?”

**Prognosis:** “I’m worried that time may be short.”

or “This may be as strong as you feel.”

“What are your most important goals if your health situation worsens?”

“What are your biggest fears and worries about the future with your health?”

“What gives you strength as you think about the future with your illness?”

“What abilities are so critical to your life that you can’t imagine living without them?”

“If you become sicker, how much are you willing to go through for the possibility of gaining more time?”

“How much does your family know about your priorities and wishes?”

“It sounds like _________ is very important to you.”

“Given your goals and priorities and what we know about your illness at this stage, I recommend...”

“We’re in this together.”
The Serious Illness Care Program

Tools
- Serious Illness Conversation Guide
- Clinician Reference Guide
- Patient preparation materials
- Family Comm. Guide

Education
- Train-the-Trainer
  - Course 101
  - Course 201
- Train Clinicians
  - Primary Clinician Training (2.5 hours)

Systems Change
- Patient Identification
- Reminder System
- Conversation using the Guide
- Document Conversation
- Patient & Family Support

Measurement and Improvement (QI)
The intervention is feasible, acceptable, and effective in stimulating more, better, and earlier conversations about serious illness goals

- Identifying the appropriate patients
- Training program is adopted and viewed as effective by clinicians.
- Reminder system stimulates discussions with a vast majority of patients within 2 visits.
- Patients and clinicians find the intervention acceptable.
- The intervention results in *more, better, and earlier* conversations about serious illness care values and goals.
- The intervention results in more comprehensive and retrievable documentation in the EMR

Multi-site quality improvement collaborative

• Medicine CTUs: Hamilton, Calgary, Montreal

• Is SICP improving:
  – Number and quality of goals-of-care conversations
  – Patient experience: being “heard and understood”
  – Clinician experience
  – Health resource use
## Variation in implementation

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<th>Calgary</th>
<th>Montreal</th>
<th>Hamilton</th>
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<td><strong>Project lead(s)</strong></td>
<td>3 MDs</td>
<td>1 MD</td>
<td>1 MD</td>
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<tr>
<td><strong>Unit champion</strong></td>
<td>0.2 FTE, CFN</td>
<td>0.3 FTE, in-kind</td>
<td>1.0 FTE, partner cash</td>
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<tr>
<td></td>
<td>(“Charge nurse”)</td>
<td>(Nurse educator)</td>
<td>(Bedside nurse: RPN)</td>
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<tr>
<td><strong>Project manager</strong></td>
<td>0.1 FTE, in-kind</td>
<td>0.1 FTE, in-kind</td>
<td>0.2 FTE, CFN</td>
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<tr>
<td><strong>Implementation team</strong></td>
<td>Medium size (15)</td>
<td>Lean (7)</td>
<td>Large (bloated?) (23)</td>
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<td><strong>Ethics review</strong></td>
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<td>Exempt</td>
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<td><strong>EMR</strong></td>
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<tr>
<td><strong>Provincial ACP Policy</strong></td>
<td>Yes</td>
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<td>No</td>
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Implementation is a Journey

Serious Illness Care Program Implementation Roadmap

**Phase One: Build Foundation**
- Convene an Exploratory Committee
- Assess Readiness
- Engage Leaders and Colleagues
- Determine Program Goals
- Recruit Implementation Team
- Select Pilot Sites
- Create Drivers for Program Use
- Construct Budget and Obtain Approval

**Phase Two: Plan Implementation**
- Plan Outreach and Communication Strategy
- Develop a Training Plan for Frontline Clinicians
- Recruit Trainers
- Modify the EHR
- Plan for Performance Improvement
- Prepare for Quality Control
- Prepare for Monitoring and Evaluation
- Customize Clinic Workflow for Conversation

**Phase Three: Launch Pilot Sites**
- Initiate Promotional Events and Activities
- Begin Clinician Training
- Implement and Refine Clinic Workflow
- Identify Clinic-level Champions
- Debrief and Synthesize Lessons Learned
- Create a Plan for Program Expansion

**Phase Four: Expand, Support & Evaluate**
- Promote the Program
- Expand to New Sites (Phased)
- Coach, Debrief, & Improve
- Plan for Sustainability
- Evaluate Impact
Adapting SICP for medicine program @ HGH

Clinicians Select Patients (Prognosis < 1 yr)

Clinician Training (SICG)

Clinician Prompt (Email, Guide)

Patient Prepared

Conversation Delivered

Document In EMR

Family Communication Guide

In EMR

Conversation Delivered
202 Conversations Delivered

• 202 conversations delivered to date by 52 different clinicians (approx. 80% physicians and nurse practitioners)

• Median length of conversation: 60 minutes

• Majority of conversations triggered by clinical team (PT, OT, SW, RN, MD)
CONSULTATION REPORT

DATE OF CONSULTATION: 24/7/2017

This is a note to summarize a Goals of Care discussion that I had during a family meeting with the patient and her 4 children using the serious illness conversation guide.

Present at the meeting were the patient, her eldest daughter, younger daughter, and the youngest daughter. She does have a younger son named but he has in fact been hospitalized at Hamilton General Hospital because of a complication of a recent coronary artery bypass graft surgery. Dr. Internal Medicine, was also present as was our unit champion for the Serious Illness Care Program.

1. Illness understanding:
Mrs. described a 1-year history of a slow functional decline to the point where she is doing less and less around the house and only able to get out of the house on Sundays when her daughter, with whom she lives, is able to take her out. Some of the other children are also pitching in to take her out of the house, but she is becoming more and more socially isolated. She describes feeling more unwell now than when she first came into hospital a few weeks ago with generalized malaise and a finding of new onset atrial fibrillation. A lot of the trouble she is experiencing now is the lack of motivation to ambulate with physiotherapy, which is also compounded by lightheadedness with walking, generalized weakness, low back pain which has been a longstanding problem since a fall 1 year ago. Her children also endorsed a steady decline over the last year in her function. She is now requiring a walker to ambulate and is having some difficulty navigating the stairs at home where she is now living for the past several years.

2. How much information would she like about what is likely to be ahead with her illness:
She was open to hearing more about the future.

3. Prognosis:
I shared with Mrs. and her family that although we are hoping that we can make some gains in her physical functioning that I am worried that this may be currently as strong as she might feel. The children also expressed this concern and acknowledged that over the past year, certainly has worsened in terms of her function.

4. What are her most important goals if her health situation were to worsen:
Mrs. response to this question is that if her health were to worsen, she wished...
“Over the past 2 days, how much have you felt heard and understood by the doctors, nurses, and hospital staff?”

Pre SIC (N=60)  Post SIC (N=56)
Patient and family experience (n=24)
Q10 In general, when I finish the discussion using the Serious Illness Conversation Guide, I think the conversations made my patients' emotional state:

Answered: 25    Skipped: 1

- Much better
- Better
- Slightly better
- Neither worse nor better
- Slightly worse
- Worse
- Much worse
“Usually, it’s like, ... you know, “What do you want? ”... But this is a bit different, which is the right thing to do. I really love the idea of exploring the...the fears, you know, and the support and what drives you and what are you afraid of. You know, what do you want to keep; what do you want to lose; what would you trade off, right? That...middle part of the conversation is very useful. ”—Physician

“ It makes my work very meaningful, especially when we’re able to accomplish something that the patient really wants ... So, it has quite a purpose for me that way.” —Nurse practitioner
## Health resource use

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<th>Intervention (n=42)</th>
<th>Control (n=56)</th>
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<tr>
<td><strong>Index hospitalization</strong></td>
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<tr>
<td>Median length of stay, days (IQR)</td>
<td>31 (18-49)</td>
<td>52 (21-87)</td>
<td>0.01</td>
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<tr>
<td>Median ALC days (IQR)</td>
<td>5 (0-18)</td>
<td>22 (0-50)</td>
<td>&lt;0.001</td>
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<tr>
<td>Median non-ALC days (IQR)</td>
<td>19 (13-33)</td>
<td>17 (9-33)</td>
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<tr>
<td><strong>Re-admission within 60 days</strong></td>
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<tr>
<td>Median length of stay, days (IQR)</td>
<td>6 (4-11)</td>
<td>19 (13-36)</td>
<td>0.17</td>
</tr>
<tr>
<td>Median non-ALC days (IQR)</td>
<td>5 (2-6)</td>
<td>19 (13-33)</td>
<td>0.01</td>
</tr>
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</table>

Comparisons between SICP (intervention) and pre-SICP (control) patients for number of repeat ED visits, intensive care unit admissions, investigations, and interventions were insignificant.
MONTREAL

• TEAM MEMBERS
  – DEV JAYARAMAN
  – LAURENCE GREEN
  – STEPHANIE SERRADA (CNS)
  – HODA HUSSEIN (ANM 15)
  – LETICEA CALPITO (ANM 17)
  – CHRISTINA MIIOUSSE (NURSE MANAGER)
  – JAMES VATISTAS (DATA MANAGER)
  – LOUISE ULYATTE (RESEARCH ASSISTANT)
PROCESS

• TRIGGERED BY ANMs DURING MULTI-DISCIPLINARY ROUNDS
• MEETING ORGANIZED BY SW/ANM/PHYSICIAN
• ESSENTIAL COMPONENTS AT THE MEETING: PHYSICIAN, PATIENT/FAMILY, NURSE/ANM (SW, PT/OT, CNS AS APPROPRIATE)
• SICG COPIES IN 15 AND 17 CONFERENCE ROOMS
MONTREAL (MGH SITE)

ANM
• Screens patients on unit for potential candidacy
• Flags appropriate patients during am multi-disciplinary rounds
• Flags appropriate patients to social worker
• Flags appropriate patients to CNS for pre-emptive involvement

Social worker
• Organizes family meeting
• Communicates decisions made during meeting with ANM if SW present at meeting

CNS
• Screens patients on the unit for potential candidacy in collaboration with ANM
• Gets involved with patient/family who would benefit from pre-emptive interventions/education regarding the program/understanding of illness
• Monitors progression and implementation of the program, reports to program directors

Resident
• Responds to social worker request for meeting, provides availabilities for meeting date/time
• Chairs serious illness conversation meeting with patient/family, team members as needed
• Documents meeting in patient chart

Staff physician
OBSERVATIONS

• COMPLETED 16 patients/7 weeks
• ABOUT HALF DONE BY RESIDENTS
• OFTEN FOCUS STILL ON LOI
• UNCOMFORTABLE USING THE GUIDE
• PREVIOUS LOI CITED AS REASON NOT TO HAVE GoC CONVERSATION
Réviser lors de tout changement d'état de santé ou à la demande de l'usager/représentant en utilisant un nouveau formulaire.

### Aptitude à discuter des niveaux de soins

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<tr>
<th>Option</th>
<th>Question</th>
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<tbody>
<tr>
<td>Apte</td>
<td>Mandat homologué: Curatelle publique/privée; Nom:</td>
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<tr>
<td>Inapte</td>
<td>Mineur de moins de 14 ans Nom du tuteur, lien:</td>
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### Volontés antérieures

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<th>Option</th>
<th>Question</th>
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<tr>
<td>Aucune disponible</td>
<td>Niveau de soins antérieur Directive médicale anticipée Testament de vie, autre</td>
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### Niveaux de soins: cocher et fournir les détails dans l'encadré

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<tr>
<td>Objectif A: Prolonger la vie par tous les soins nécessaires</td>
<td>Donner au besoin dans l'encadré des détails sur des soins particuliers.</td>
</tr>
<tr>
<td>Objectif B: Prolonger la vie par des soins limités</td>
<td>Par exemple : hémodialyse, transfusion sanguine, soutien nutritionnel (entéral ou parentéral), soins préventifs, etc.</td>
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<tr>
<td>Objectif C: Assurer le confort prioritairalement à prolonger la vie</td>
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<tr>
<td>Objectif D: Assurer le confort uniquement sans viser à prolonger la vie</td>
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### Réanimation cardiorespiratoire (RCR): cocher et fournir au besoin les détails dans l'encadré

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<td>Arrêt cardiaque (circulatoire)</td>
<td>Cocher si NON désiré : pour guider les soins préhospitaliers aux objectifs B et C (voir au verso)</td>
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<tr>
<td>Tenter la RCR</td>
<td>PAS d'intubation d'urgence (objectifs B et C seulement)</td>
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<tr>
<td>Ne PAS tenter la RCR</td>
<td>PAS d'assistance ventilatoire si inconscient (objectif C seulement)</td>
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### Notes explicatives sur la discussion et consignes concernant des soins particuliers

<table>
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<tr>
<th>Discuté avec:</th>
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<th>Représentant</th>
<th>Nom</th>
<th>Lien</th>
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<td>Coordonnées</td>
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Rapporter les noms des participants ainsi que les mots utilisés pendant la discussion et toute information qui aide à préciser les volontés.
TRAINING

• 8 PHYSICIANS TRAINED (65 % OF ROUNDING TIME THIS YEAR)
• MEET WITH SENIOR RESIDENTS EACH PERIOD AND TRAIN
• PLAN FOR AHD IN JANUARY
• TRAIN THE TRAINER SESSION?
Serious Illness Conversation Guide: 8 clicks

- **Understanding**
  - What is your understanding of where you are with your illness?

- **Information Preferences**
  - For example: Some patients like to know about, others like to know what is expected, others like to know both.
  - How much information about what is likely to be ahead with your illness would you like from me?

- **Proposed Communication**
  - What did you communicate to the patient?

- **Goals**
  - For example: Being at home, being mentally aware, being in control of decisions, not being a burden, achieving life goals, supporting my children.
  - If your health situation worsens, what are your most important goals?

- **Fears/Concerns**
  - What are your biggest fears and worries about the future with your health?

- **Function**
  - What activities are so critical to your life that you can't imagine living without them?

- **Trade-offs**
  - For example: Being on a machine temporarily vs. being in the hospital or ICU, having a feeding tube.
  - If you become sicker, how much are you willing to go through for the possibility of gaining more time?

- **Family**
  - (Suggest bringing family and/or health care agent in to next visit to discuss together)
  - How much does your family know about your priorities and wishes?
Questions

1) It is important to invite patients to have a discussion about their prognosis when they are facing serious, life-limiting illness

**TRUE**

2) A goals-of-care conversation should focus on what procedures a patient does or does not want during serious illness

**FALSE**
Extra stuff ...
Lessons learned

• Important implementation activities:
  – One-on-one conversations critically important
  – Owning part of this problem: “It’s everybody’s business”
  – Tailoring to local context (aligning with hospital, regional priorities and activities, e.g. AUA score, QEOLC, HealthLinks)

• Observations:
  – Siloed nature of hospital vs. primary care (Hamilton)
  – Hospital culture: code status, in-the-moment decision-making
  – Surprises about who on the team will champion the program

• Looking ahead:
  – How will we make this a sustainable change?
## Patient and family experience
(n=24)

<table>
<thead>
<tr>
<th>Experience</th>
<th>Mean score (95% confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your understanding of what your health may be like in the future</td>
<td>5.5 (5.1 - 5.9)</td>
</tr>
<tr>
<td>Your sense of control over your medical decisions</td>
<td>5.1 (4.6 - 5.6)</td>
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<tr>
<td>The closeness you have with your clinician</td>
<td>4.5 (4.2 - 4.8)</td>
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<tr>
<td>your hopefulness about your quality of life</td>
<td>3.8 (3.1 - 4.5)</td>
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<tr>
<td>your understanding about your life expectancy</td>
<td>5.5 (5.0 - 6.0)</td>
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<tr>
<td>Your sense of peacefulness</td>
<td>4.6 (4.1 - 5.2)</td>
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