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

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MUHC Medical Grand Rounds
October 23, 2018

CARENET
Canadian Researchers at the End of Life Network

Canadian Frailty Network | Réseau canadien des soins aux personnes fragilisées

Known previously as Technology Evaluation in the Elderly Network, TVN

McMaster University HEALTH SCIENCES

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

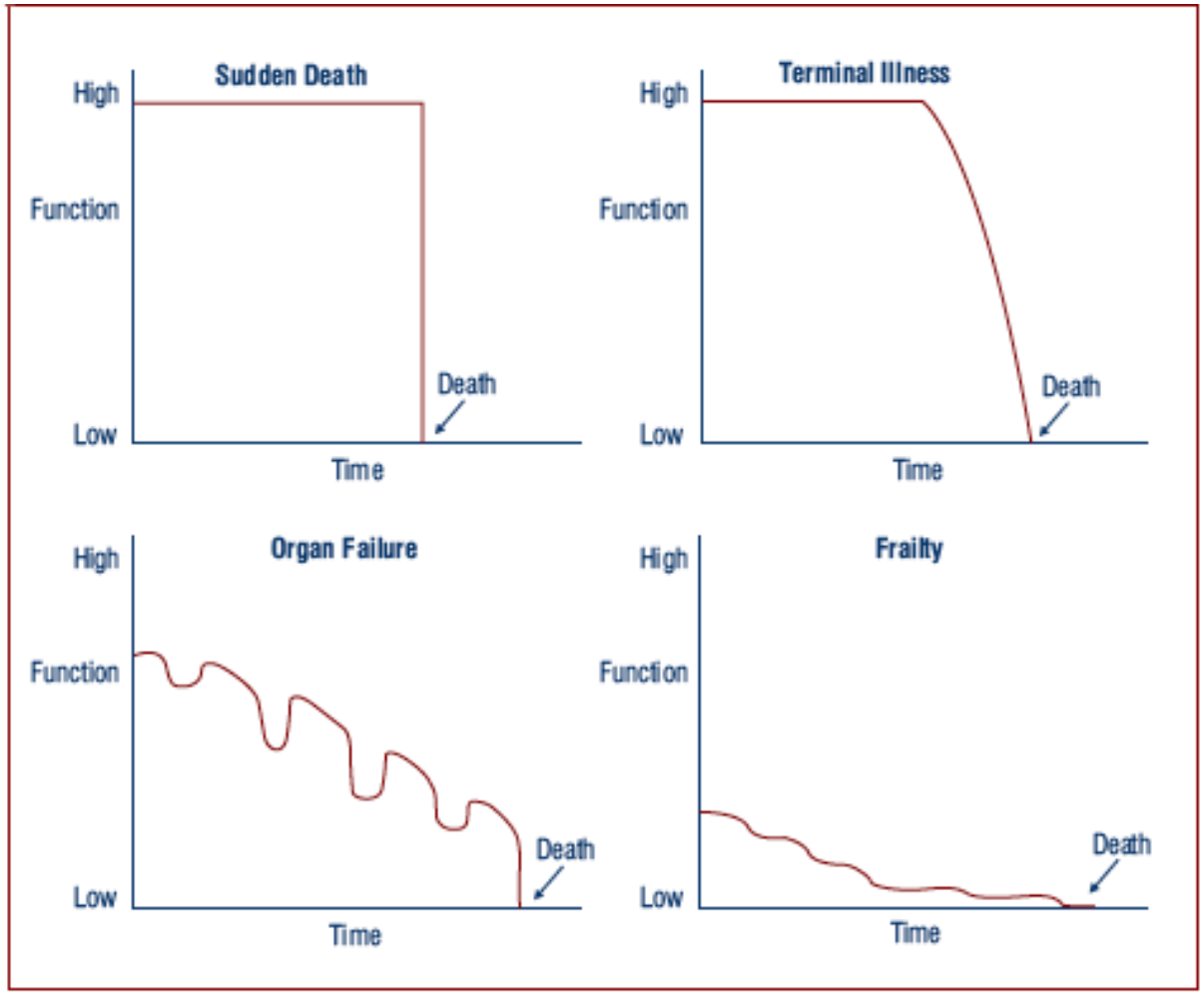
2) A goals-of-care conversation should focus on what procedures a patient does or does not want during serious illness

   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



Source: J. Lunney, J. Lynn, C. Hogan, "Profiles of Older Medicare Decedents." *Journal of the American Geriatric Society*, 50 (2002), pp. 1108–1112.

CMAJ RESEARCH

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.

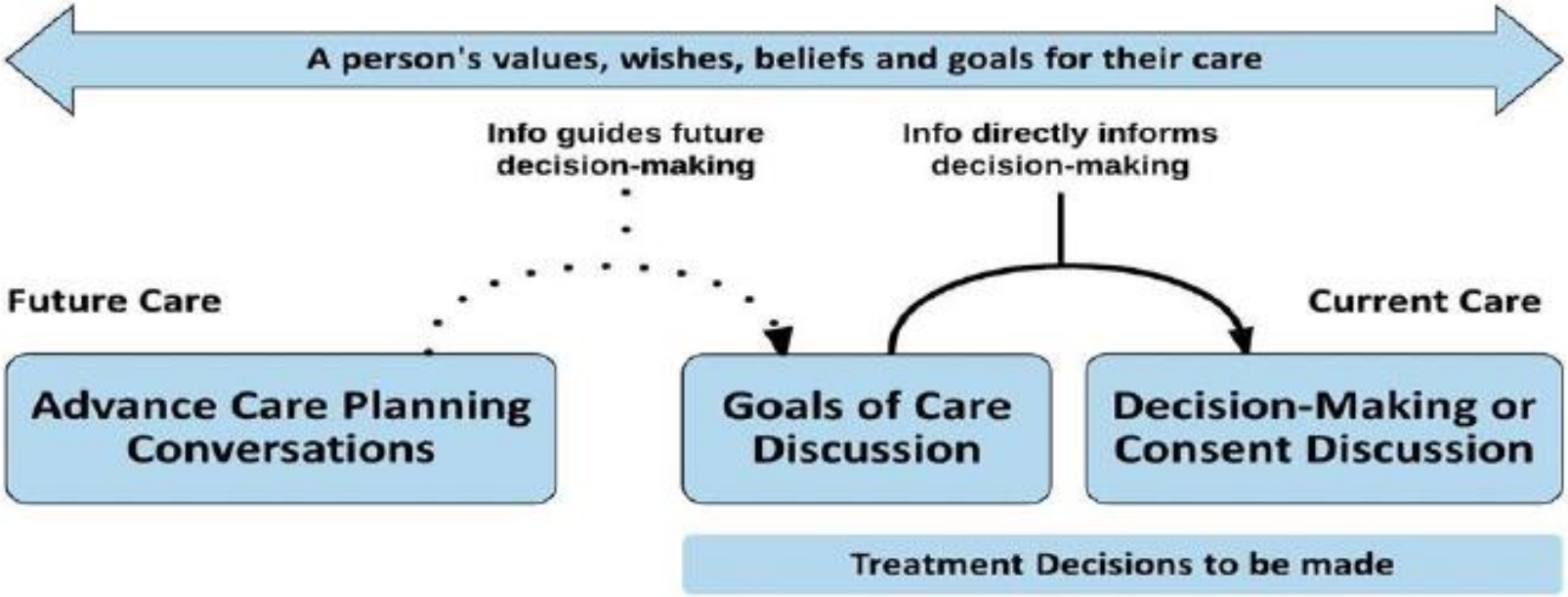


Figure: Relationship between three discussions that contribute to informed consent

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ORIGINAL RESEARCH

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 Dodek[5]

Heyland DK et al. BMJ Qual Saf 2015.

Study participants

	Patients N=808
Age, years, mean (SD)	80 (9.4)
Female, n (%)	455 (56.3)
Caucasian, n (%)	765 (94.7)
Charlson Comorbidity Index, mean (SD)	2.8 (2.6)
Frail, n (%)	280 (34.7)
Health Literacy (REALM-R score), mean (SD)	7.3 (1.5)
Inclusion criteria, n (%)	
Age 55+ with advanced chronic disease (e.g. COPD)	319 (39.5)
Age 80+	477 (59.0)
Would not be surprised if died < 6 months	12 (1.5)

Heyland DK et al. BMJ Qual Saf 2015.

Are medical errors common?

	Patients						
		Documented goals*					
	Preferences*	1	2	3	4	None	Total
All possible treatments including CPR	1	**56**	0	7	1	**28**	92
ICU admission, No CPR	2	26	**3**	34	3	7	73
Full medical treatment, No CPR	3	20	3	**74**	8	36	141
Comfort oriented treatment, No CPR	4	34	8	85	**16**	51	194
	Total	136	14	200	28	122	500

Crude agreement = 35%

1 in 3 patients experience a medical error

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Potential under-treatment = 1.6%

Potential over-treatment = 34.8%

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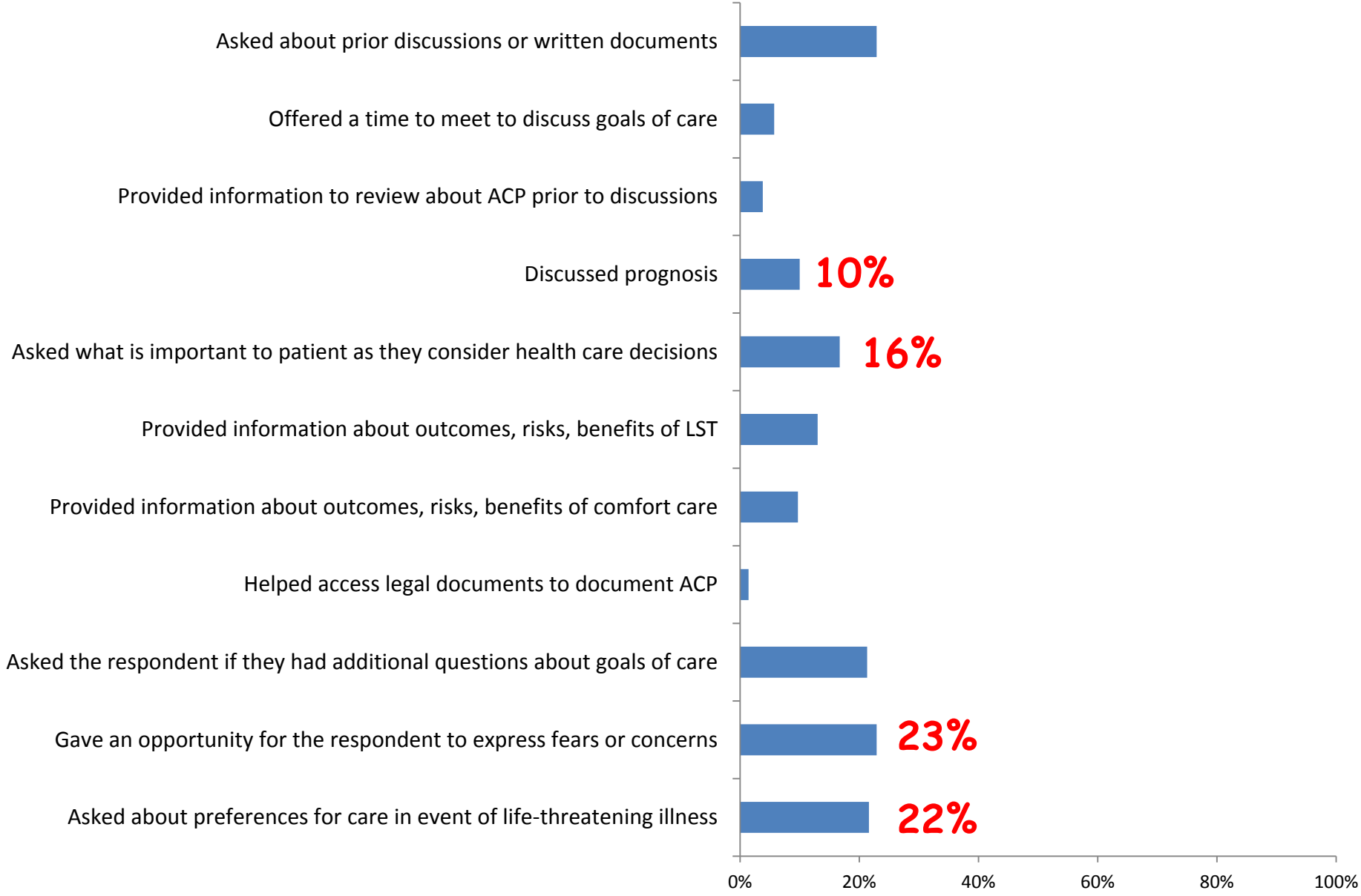


You JJ et al. CMAJ 2014.

Common barriers to goals of care (GoC) discussions …

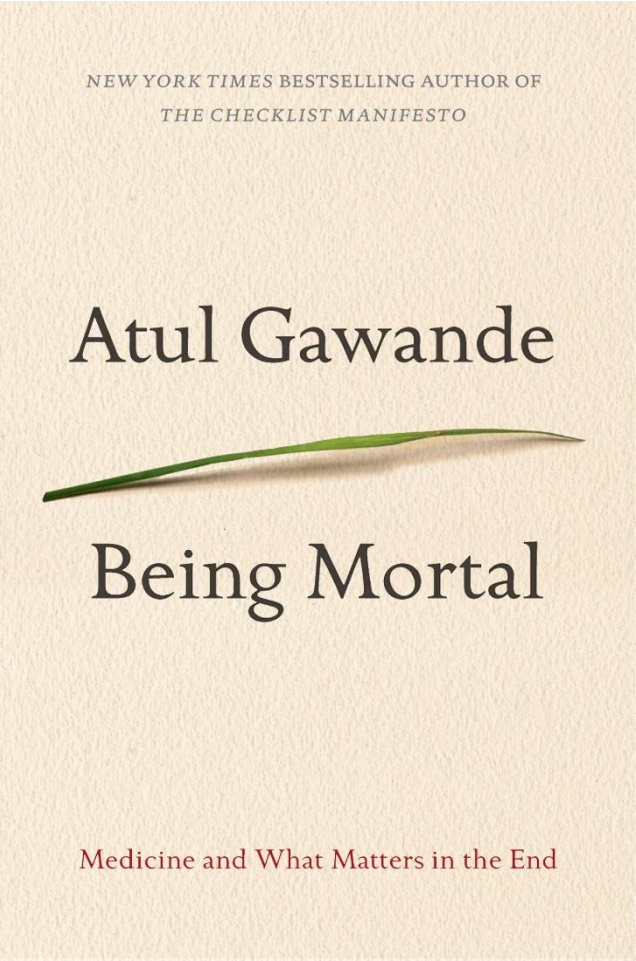
Clinicians uncomfortable initiating GoC discussions

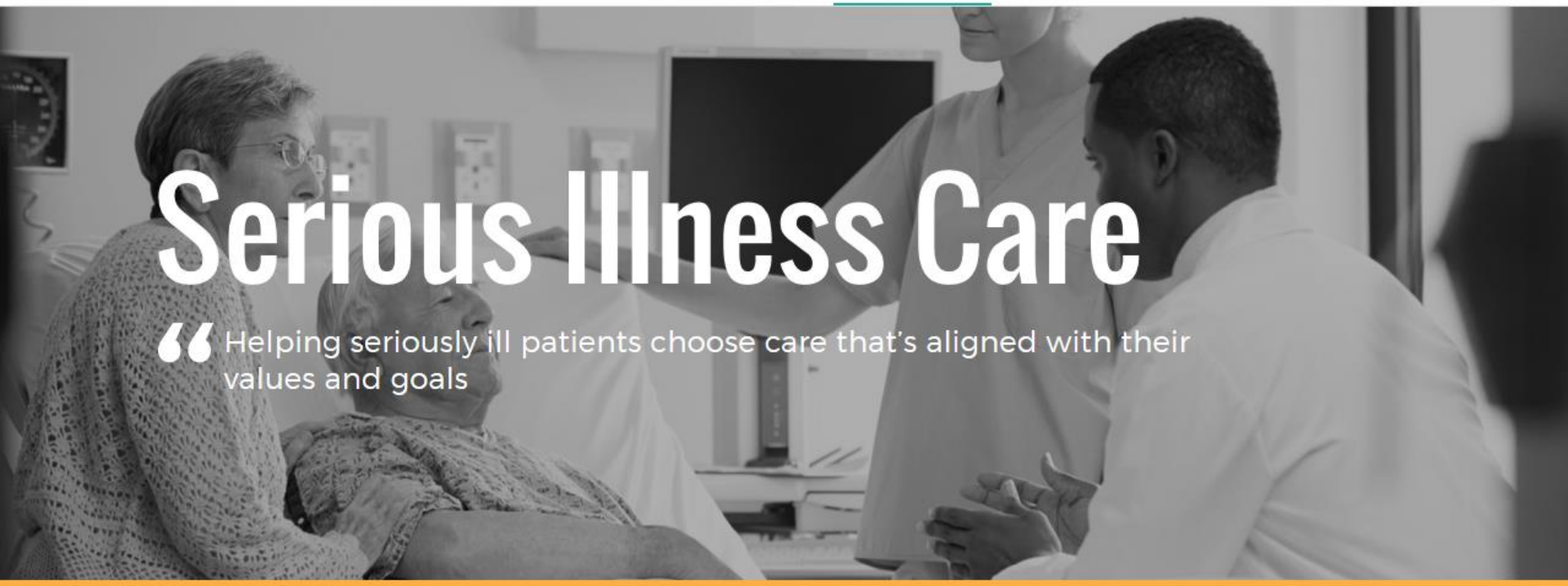
Emotional barriers that impede patients from engaging in GoC discussions

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


NEW YORK TIMES BESTSELLING AUTHOR OF
THE CHECKLIST MANIFESTO
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

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP

"I'm hoping we can talk about where things are with your illness and where they might be going — **is this okay**?"

ASSESS

"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?"

SHARE

Prognosis: "I'm worried that time may be short."
or "This may be as strong as you feel."

EXPLORE

"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?"

CLOSE

"**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**."

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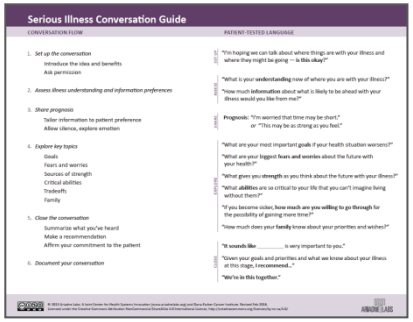
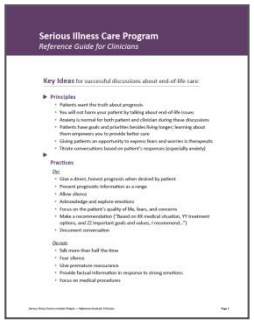
ARIADNE LABS

The Serious Illness Care Program

Tools

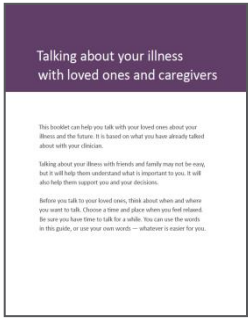


Serious Illness Conversation Guide



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

Bernacki R, Paladino J, Lamas D, et al. Palliative Care in Oncology Symposium, Boston, MA, 2015.

Multi-site quality improvement collaborative

- Medicine CTUs: Hamilton, Calgary, Montreal

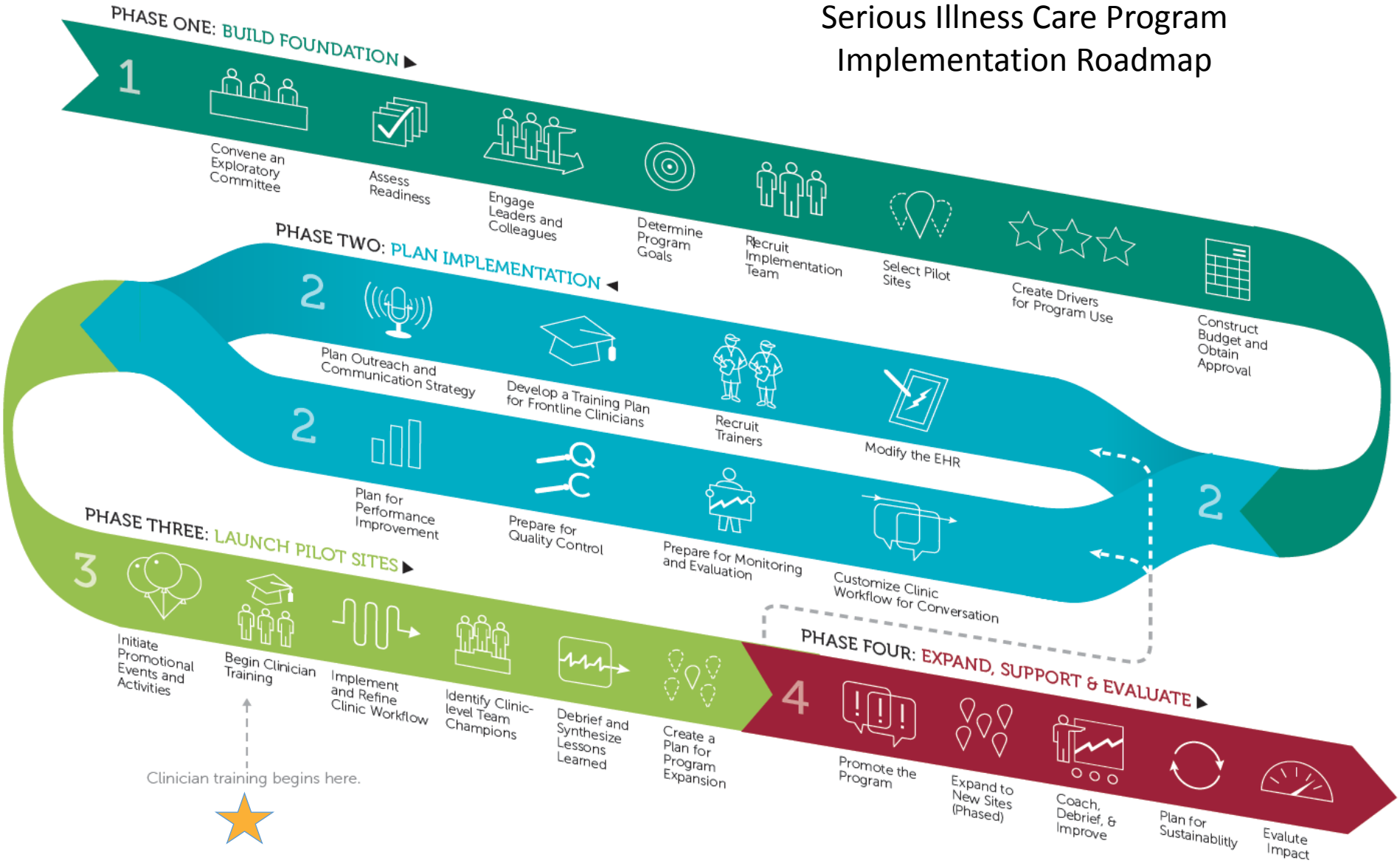
- Is SICP improving:
  - Number and quality of goals-of-care conversations
  - Patient experience: being “heard and understood”
  - Clinician experience
  - Health resource use

Variation in implementation

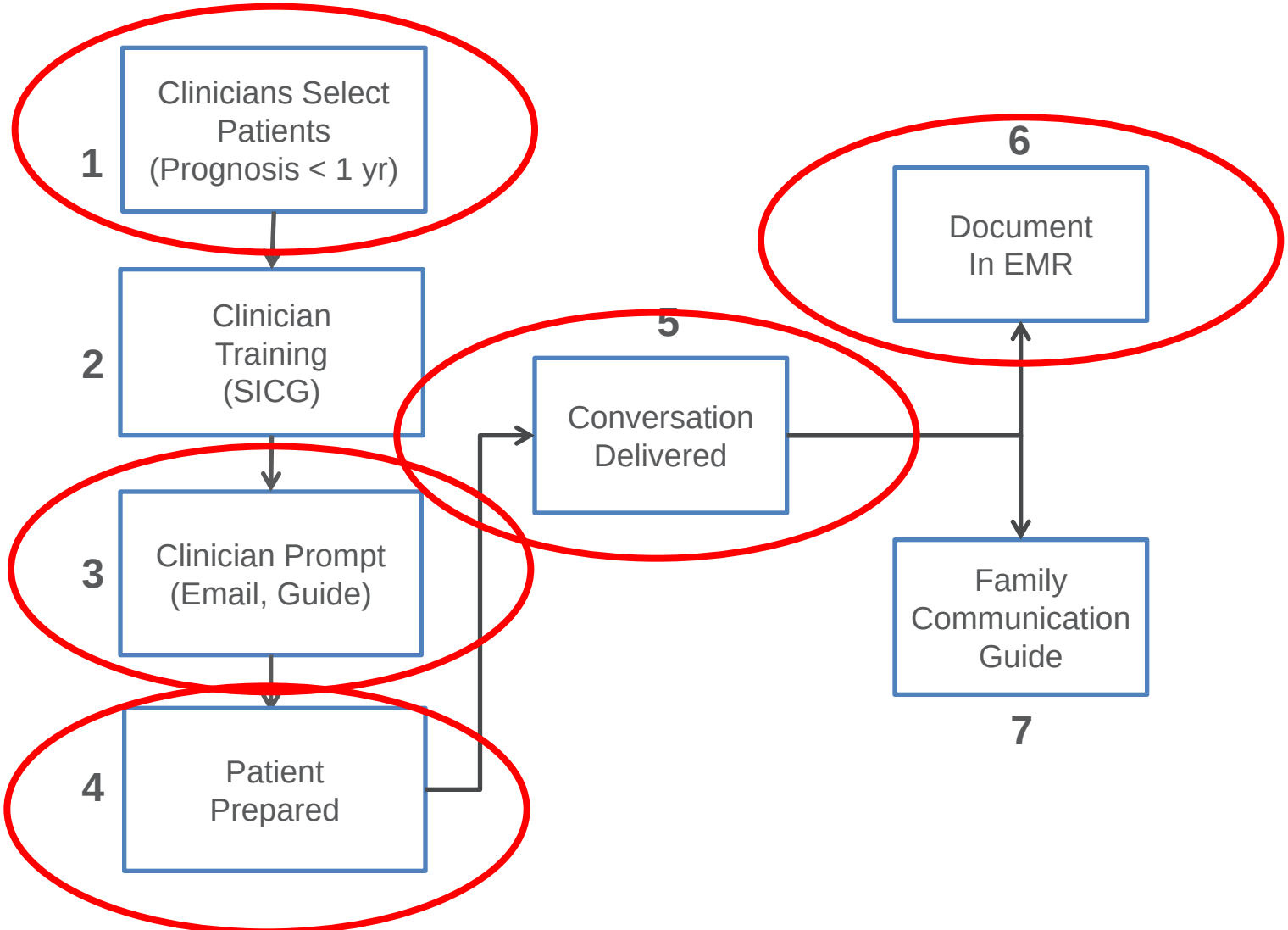
	Calgary	Montreal	Hamilton
Project lead(s)	3 MDs	1 MD	1 MD
Unit champion	0.2 FTE, CFN (“Charge nurse”)	0.3 FTE, in-kind (Nurse educator)	1.0 FTE, partner cash (Bedside nurse: RPN)
Project manager	0.1 FTE, in-kind	0.1 FTE, in-kind	0.2 FTE, CFN
Implementation team	Medium size (15)	Lean (7)	Large (bloated?)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

Implementation is a Journey

Serious Illness Care Program
Implementation Roadmap



Adapting SICP for medicine program @ HGH



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

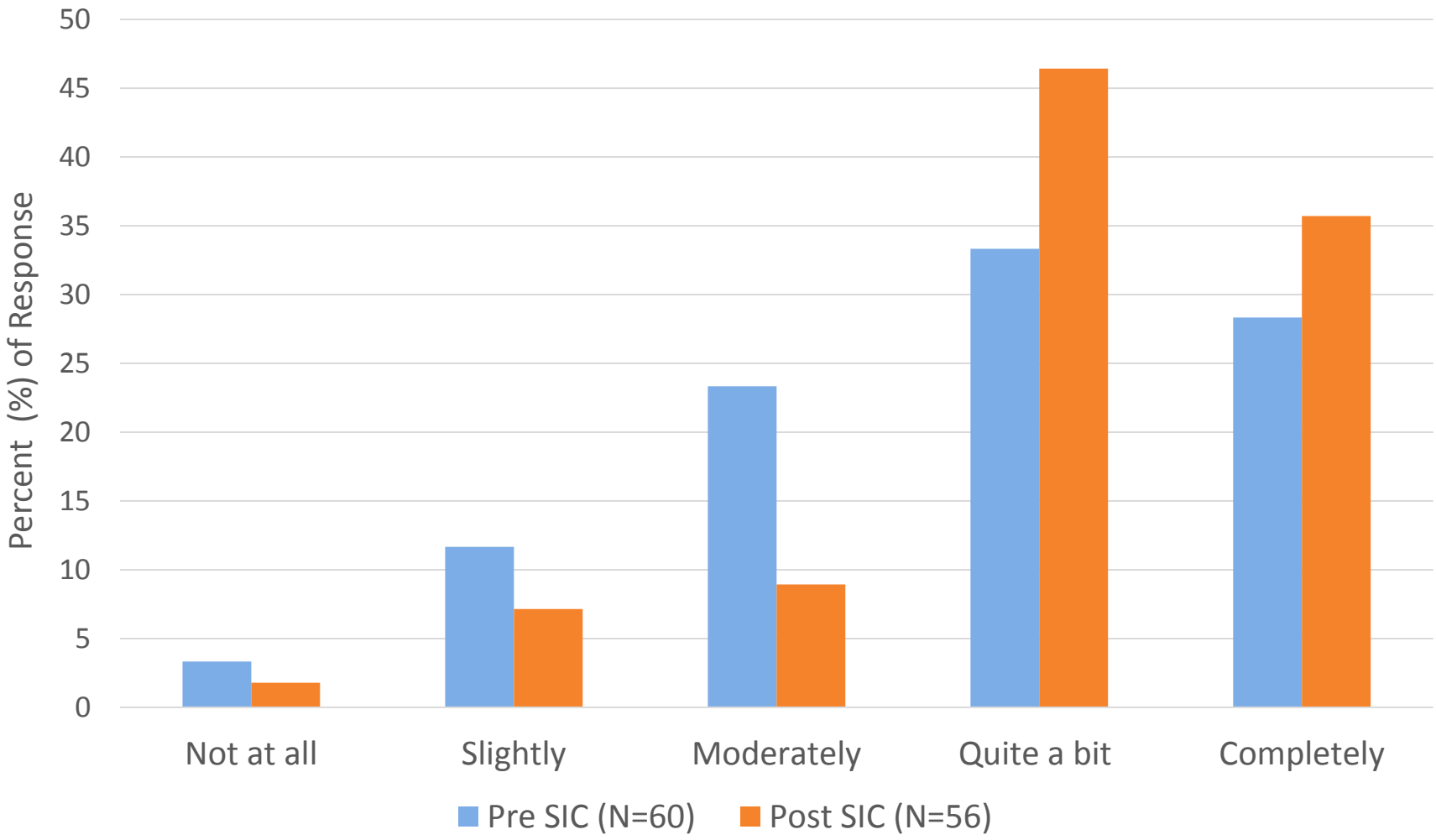
1. Illness understanding:
Mrs. [redacted] described a 1-year history of a slow functional decline to the point where she is doing less and less around the house and only able to get out of the house on Sundays when her daughter, [redacted], with whom she lives, is able to take her out. Some of the other 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 [redacted] 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.

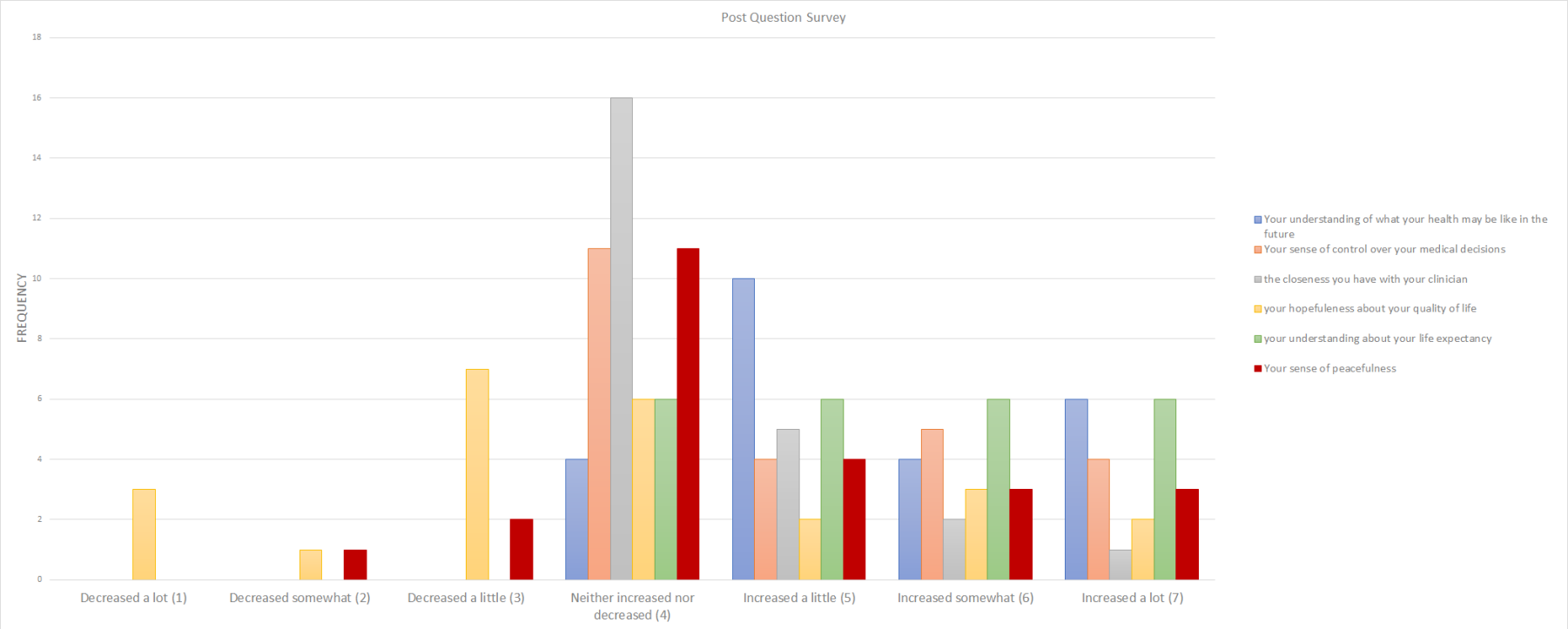
3. Prognosis:
I shared with Mrs. [redacted] and her family that although we are hoping that we can make some gains in her physical functioning that I am worried that this may be currently as strong as she might feel. The children also expressed this concern and acknowledged that over the past year, Mrs.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

4. What are her most important goals if her health situation were to worsen:
Mrs. [redacted]' 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?"

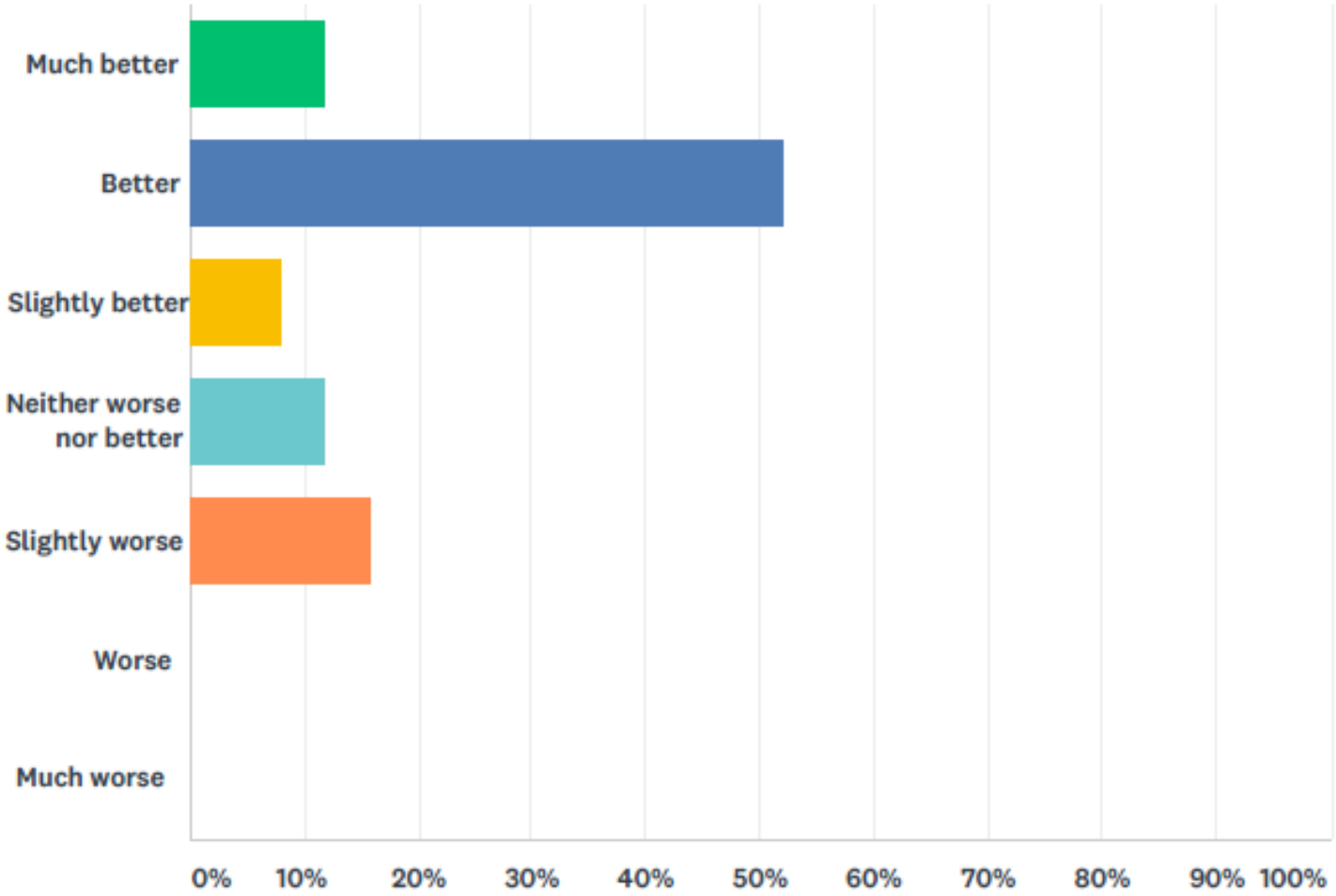


Patient and family experience (n=24)



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



"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

	Intervention (n=42)	Control (n=56)	P
Index hospitalization			
Median length of stay, days (IQR)	31 (18-49)	52 (21-87)	0.01
Median ALC days (IQR)	5 (0-18)	22 (0-50)	<0.001
Median non-ALC days (IQR)	19 (13-33)	17 (9-33)	0.59
Re-admission within 60 days			
Median length of stay, days (IQR)	6 (4-11)	19 (13-36)	0.17
Median non-ALC days (IQR)	5 (2-6)	19 (13-33)	0.01

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 MIOUSSE (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
Staff physician

- 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

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

☐ Apte ☐ Inapte : ☐ Mandat homologué ☐ Curatelle publique/privée; Nom : _____

☐ Mineur de moins de 14 ans Nom du tuteur, lien : _____

Volontés antérieures : ☐ Aucune disponible ☐ Niveau de soins antérieur ☐ Directive médicale anticipée ☐ Testament de vie, autre

Niveaux de soins : cocher et fournir les détails dans l'encadré *(Notes explicatives au verso)*

☐ Objectif A : Prolonger la vie par tous les soins nécessaires ☐ Objectif B : Prolonger la vie par des soins limités ☑ Objectif C : Assurer le confort prioritairement à prolonger la vie ☐ Objectif D : Assurer le confort uniquement sans viser à prolonger la vie	Donner au besoin dans l'encadré des détails sur des soins particuliers. *Par exemple : hémodialyse, transfusion sanguine, soutien nutritionnel (entéral ou parentéral), soins préventifs, etc.*

Réanimation cardiorespiratoire (RCR) : cocher et fournir au besoin les détails dans l'encadré *(Notes explicatives au verso)*

Arrêt cardiaque (circulatoire)	**Cocher si NON désiré : pour guider les soins préhospitaliers aux objectifs B et C** *(voir au verso)*
☐ Tenter la RCR ☑ Ne PAS tenter la RCR	☑ PAS d'intubation d'urgence (objectifs B et C seulement) ☐ PAS d'assistance ventilatoire si inconscient (objectif C seulement)

Notes explicatives sur la discussion et consignes concernant des soins particuliers

Discuté avec : ☐ Usager ☐ Représentant | Nom Son. | Lien

Coordonnées

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: 6 clicks

NoteWriter

SICG Note

Serious Illness Conversation Guide

Understanding

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

Information Preferences

FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.

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

Prognosis 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 goal, supporting my children.

If your health situation worsens, what are your most important goals?

- ☐ live as long as possible, no matter what
- ☐ be physically comfortable
- ☐ not be a burden
- ☐ have their medical decisions respected
- ☐ be spiritually and emotionally at peace
- ☐ be at home
- ☐ be mentally aware
- ☐ be independent
- ☐ provide support for the family
- ☐ achieve particular life goal (see comments)

Fears/Worries

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

- ☐ pain
- ☐ concerns about meaning of life
- ☐ loss of control
- ☐ finances
- ☐ spiritual distress
- ☐ other family concerns
- ☐ preparing for death
- ☐ emotional distress
- ☐ ability to care for others
- ☐ loss of dignity
- ☐ other symptoms
- ☐ burdening others
- ☐ getting unwanted treatments
- ☐ other (see comments)

Function

FOR EXAMPLE: Ability to eat, recognize or interact with others, be aware, or care for yourself.

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

- ☐ being conscious
- ☐ being without pain or great discomfort
- ☐ being able to care for myself, such as toileting and feeding
- ☐ being able to interact with others
- ☐ being able to talk
- ☐ being able to be myself

Trade-offs

FOR EXAMPLE: Being on a machine temporarily versus permanently, 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?

- ☐ aggressive tests and/or procedures
- ☐ feeding tube
- ☐ hospital
- ☐ ICU
- ☐ nursing home
- ☐ being uncomfortable
- ☐ ventilator

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)

	Mean score (95% confidence interval)
	1=decreased a lot, 7=increased a lot
Your understanding of what your health may be like in the future	5.5 (5.1 - 5.9)
Your sense of control over your medical decisions	5.1 (4.6 - 5.6)
The closeness you have with your clinician	4.5 (4.2 - 4.8)
your hopefuleness about your quality of life	3.8 (3.1 - 4.5)
your understanding about your life expectancy	5.5 (5.0 - 6.0)
Your sense of peacefulness	4.6 (4.1 - 5.2)