Serious Illness Communication

This visual summary highlights gaps in serious illness communication. It stresses the need for personalized communication and the importance of caregiver advocacy, considering patients' diverse backgrounds. This knowledge translation aims to improve education, and health systems for better patient-centered care.

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Patient Experience
Patient Partnerships

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The design work for this project was done by Eliot El Zeinaty.

Objectives

The study aims to characterize the **documentation** and **experiences** of serious illness conversations, encompassing code status, goals of care, advance care planning, and values-based discussions, from the perspectives of both patients with cancer and those on general internal medicine (GIM) wards.

Methods

Our team **reviewed** hospital chart data, **surveyed** clinicians, and **interviewed** patients and caregivers.

Results

Ninety-seven completed survey; 56% were physicians, 32% were nurses, and 12% were allied health (social work, occupational therapy, physical therapy, etc.)

Table 1: Demographics of Clinician Participants

	Total Clinician	
Ratial/ethnic group[1]	%	
White	29	
Other Racial/Ethnic Group	61	
Prefer not to answer/ Do not Know	10	
Gender	32 M	66 F
Years Of Practice Mean ± Standard deviation	8.3 ± 7.6	
Importance of Spirituality or Religion in life		
Somewhat Important/ Very Important/ Extremely Important	54*	
Prefered Language - English	94	

*21% Answered as Prefer not to answer or Not Applicable.
1 Detailed racial/ethnic identities collapsed into categories given <5 responses/category

Top Five Reported Barriers to Serious Illness Conversations:

1. Language barriers
2. Uncertainty in estimating prognosis
3. Lack of time to have conversations
4. Perceived discomfort to discuss GoC in some cultures
5. Lack of agreement amongst family members about Goals of care (GoC)

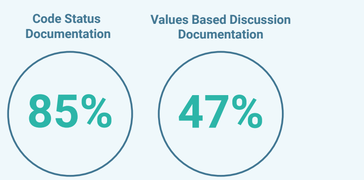
EMR Chart Review

We reviewed the charts of the hospitalized patients between August 2022 and March 2023 for the following data:

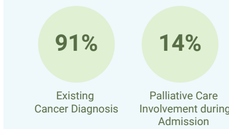
- Cancer Diagnosis
- Preferred Language
- Code Status
- Length of Stay
- Performance Status — PPS* (*Palliative Performance Scale): 100% Fully ambulatory; 0% Death

We also collected data on patients' understanding of their:

1- Illness
2- Prognosis
3- Goals
4- Hopes
5- Concerns
6- Treatment recommendations



21 patients/caregivers were interviewed



Patient/Family Interviews

Four primary themes emerged, providing insight into the documentation and experiences of serious illness conversations:

1) Patient preferences for communication;
2) Impact of care siloes;
3) Presence of a patient advocate;
4) Lack of values-based discussions.

See below for key insights from these themes, with patient/caregiver quotes in the speech bubbles.

1 Patient Preferences for Communication

Patients have varied preferences for communication about diagnosis, treatment, and illness progression, categorized into experiences with the patient portal, tailored communication, and multiple formats. The patient portal, providing real-time access to health information, elicited mixed reactions, with some finding it overwhelming. Tailored communication involves personalizing the approach to individual needs, while sharing information in multiple formats ensures accessibility and effectiveness for different individuals.

- Patients want more context for results in the patient portal. They suggested a pop-up banner for distressing news and appreciated the portal for processing results and emotions.
- Tailored communication is essential. Some prefer empathy during serious illness conversations (SICs), while others favor a direct approach.
- Clinicians should adapt to unique communication styles. Patients prefer receiving information in various formats to suit their needs.

> [in reference to learning about a diagnosis via online portal] So I think like, it would have been better had... maybe it was broken up... broken to us by somebody and a little more. Like had they known my values of you know being an emotional person or you know, being a little more empathetic, then they could have approached it in that way a little bit.

Patient

> I also think that alternatively it helped a little bit for her to prepare the questions that [patient] wanted to ask...it gave us a chance to mentally prepare what [patient] wanted to ask, she needs some time to process stuff.

Caregiver

2 Presence of a Patient Advocate

Many patients highlighted the vital role of caregivers who offered essential assistance, such as transportation to appointments, monitoring vital signs, communicating with healthcare providers, and translating for patients. Caregivers who were interviewed highlighted their role as advocates.

> So, since he was diagnosed, I have been dealing with everything hospital related. All his visits, all his appointments. Taking him, driving him, speaking to his doctors.

Caregiver

3 Impact of Care Siloes

Some patients described challenges in coordinating care between their inpatient and outpatient clinicians. Others described the impact of frequent staff turnover in the academic teaching hospital, and they also identified a lack of communication between their different clinicians and its impact on serious illness communication.

> You know, you go from doctor to doctor from nurse to nurse. And you get asked the same questions, over and over and over and over again, like, you tell the same story, like, do people not take notes?

Patient

4 Lack of values-based discussions

Many patients often associated serious illness conversations with do not resuscitate orders. Most did not discuss their care values with clinicians. One caregiver noted missed opportunities for the care team to address these topics. Some patients were not ready or did not see the need for values-based discussions during their admission, while others wanted these discussions but had to initiate them themselves.

> It's always been about the specific treatment, you know, what's going on at the time, it's always medical. It's always about what's going on at the time. But then as I said I'm just coming up to the point now where they are saying uh you might not do so well this time. You know? And so, whether they've got things planned down the road, I don't know. To this point I've had none of it [values-based discussions]. I don't really need any of it right now. But, it's a good idea.

Patient

Co-Design Highlights

1st Workshop
Exploring and prioritizing the key issues in serious illness conversations. By gathering insights from various stakeholders, we identified the most critical gaps and areas for improvement.

2nd Workshop
Building the experience through collaborative ideation and journey mapping. Participants worked together to develop innovative solutions, guided by the design principles established in the initial session.

3rd Workshop
Refining these collaborative ideas. We detailed the proposed interventions, discussed potential barriers and facilitators, and outlined actionable steps to implement the new approaches.

Participants — Patients and Families - Caregivers- Clinicians

Design Principles for Talking Serious Illness

The Talking Serious Illness Journey

This journey outlines an ideal approach to serious illness conversations, divided into three phases.

1) It starts when a patient arrives at the hospital where they are provided with resources and support

2) Discussions evolve based on urgency and needs, from brief to extensive dialogues.

3) As urgency decreases, there is more opportunity for two-way conversations, enabling patients, families, and providers to ask questions and share information.

This approach ensures that conversations are documented collaboratively, aligning care with patients' values.

Urgent — Norm — Extended