Primary care communication and palliative care in the era of COVID-19

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Case description

Jenny is a 61-year-old teacher who was recently diagnosed with breast cancer and is receiving first line chemotherapy. She is a mother of 3 adult children, married, and an avid gardener. She was previously healthy, with no comorbidities, but developed a dry cough yesterday. She remains afebrile and has had no recent travel history or sick contacts. Per local public health recommendations, she is carefully monitoring her symptoms at home. After hearing conflicting information on the news and online, her husband, attempting to clarify information, calls his wife's primary care provider.

Sources of information

Our recommendations are guided by two well-recognized training programs, VitalTalk (www.vitaltalk.org) and Serious Illness Conversation Program (www.ariadnelabs.org), aimed at teaching health care providers communication-skills and providing them with clinician guides to lead serious illness conversations. Training primary care clinicians to use a patient-tested guide to lead serious illness conversations is feasible and is associated with more comprehensive conversations and increased documentation in the patient's medical record (1). Breaking down complex goals-of-care discussions into component parts can help clinicians learn effective communication skills that result in making treatment recommendations aligned with patients' hopes and wishes (2). Our recommendations are also guided by existing literature (3) and through experiences of practising palliative care (PC) specialists at an urban academic Canadian hospital.

Main message

The World Health Organization declared a pandemic in March 2020 from the novel coronavirus, SARS-CoV2. Although many family physicians worked diligently and quickly to plan for the impact of COVID-19, there were substantial challenges due to the rapidly changing screening protocols, the challenges of transitioning to virtual care, and the impact of self-isolation on health care professionals and patients alike (4). The uncertainty underlying these challenges, and the resulting anxiety, can be mitigated by clear, empathic communication. Communication skills are also essential for leading serious illness conversations, which are key to planning and managing treatment for patients during a pandemic.

Leading goals-of-care discussions with seriously ill patients and their families is a core skill taught and practiced by PC specialists, but should be a basic skill for any clinician providing primary care. Leading discussions about what matters most to people can be considered as a medical procedure with component skills that can be taught, evaluated and improved upon in order to assist clinicians in helping patients and families achieve best quality of life (5). Emerging data demonstrate that skill-based communication-specific educational interventions lead to favorable patient care outcomes (1,6-7).

Unfortunately, many practicing physicians may not have received explicit communication skills teaching for goals-of-care discussions during their medical training and subsequently many Canadians may never have been asked to discuss their preferences for future care with their doctor. Bernacki and Block describe barriers to adequate communication about serious illness care goals at the patient (e.g., denial or families trying to protect loved ones), physician (e.g., lacking time and tools to accurately prognosticate) and system (e.g., no standard means or location to document conversations, medical culture norm to pursue life-sustaining treatment) levels (8). During the pandemic, primary care clinicians will be called upon to lead timely goals-of-care discussions and while many may feel confident to do so, others may feel ill-equipped to lead these needed conversations.

The rapid evolution of the COVID-19 pandemic has highlighted the importance of serious illness conversations for family physicians. Effective and compassionate communication is especially important for clinicians that may need to make extraordinarily difficult decisions including the prioritization of limited resources. Below we describe a structured approach to goals-of-care conversations that may assist all front-line clinicians to better communicate with their patients and families during this crisis.

Anticipate emotion

Expect emotion when navigating COVID-19 discussions. Patients and families are likely to be anxious and worried as COVID-19 spreads in their regions, particularly if they are experiencing symptoms that are similar to those of COVID-19 infection. Information from government and health institutions is rapidly evolving and people are likely receiving varied messages as websites, news agencies and social media platforms struggle to keep up with the most up-to-date information. In addition, news reports tend to focus on negative outcomes and patient deaths, which may heighten patients' fears. This will likely contribute to anxiety in most patients.

Be empathic

Using evidence-based, empathic language and skills may help align you to your patients. Clinician empathy has been associated with increased patient trust in their provider (7) and may also be associated with increased patient satisfaction of care. Building trust creates a space for patients and families to listen to the important information you need to share with them. Trust is essential during a pandemic as information may change rapidly. To illustrate, patients often tell PC specialists they did not hear anything the doctor said after difficult health information was relayed (e.g., after being told their illness is incurable). Thus, clinicians should first respond to patient emotion with empathy, affording time to process emotions patients are feeling in response to the difficult news. The mnemonic NURSE provides statements that articulate empathy; examples of statements relevant to the setting of a pandemic are presented in Table 1 (9). Consider using NURSE statements in response to any identified emotions including after you have delivered serious health information. For example, if you choose to initiate a goals-of-care discussion with your patient at home living with stage IV cancer and they seem uneasy to participate in the discussion, you may say, "It sounds like you are surprised that I am calling you at home to discuss your future care preferences." Only after space is created for the patient to emote should clinicians continue to move forward through a goals-of-care conversation.

Table 1. Using NURSE[1] statements to respond to patient emotion

SKILL	EXAMPLE LANGUAGE
Name	“It sounds like you are upset to hear this news.”
Understand	“I can’t imagine how difficult it must be to hear this information.”
Respect	“I admire your strength to engage in this planning conversation.”
Support	“Our team will be here to support you during this time, and always.”
Explore	“Tell me more about how you are feeling about all of this?”

[1]Adapted from Back AL, Arnold RM, Baile WF, Tulsky JA, Fryer-Edwards K. Approaching difficult communication tasks in oncology. CA Cancer J Clin. 2005;55:164-177.

Be clear and succinct in your messaging

Share difficult health information in small chunks and be sure to associate meaning with the messages that you deliver. For example, if you need to tell someone that you are worried that their breathing could worsen, be sure to attach this information to a message describing how this news will impact them. For example, "Your wife's new cough makes me worried that her condition could worsen. I think it is important for us to discuss how our primary care team can best care for you and her should that happen. This will be important both at home and in the unfortunate event of her requiring hospital-type care." Allow this difficult information to be digested by your patients by giving time for silence.

Be curious

Asking questions to your patients and their families will show that you are listening to them and that you have a desire to participate in shared decision-making based on what matters most to them. Ask them questions about what specifically is concerning them at the present time, and how they and their family are managing. Ask them how the news they consume on social media is impacting them. Ask them how newly implemented health policies (e.g., closing of schools and businesses, inability to visit with family and friends) is affecting their ability to cope with illness. Ask them if they feel isolated, hopeless, or scared. The more you know about your patients' and their families' experiences, the more prepared you will be to support them during this uncertain time. It will also likely help you to make treatment recommendations that align with their experience and goals.

Address goals of care early

If planning has not been initiated and documented previously, then it should be done now. When discussing goals-of-care in a PC setting, PC specialists often hear, "why did my providers not bring this up sooner with me?" Many Canadians have already had discussions about end of life wishes with their loved ones and it is our shared responsibility to ask them about these wishes. Given the uncertainty related to COVID-19, acknowledging the situational uncertainty, exploring patient values as above, and documenting these discussions in the patient's medical record - ideally in a location that is easily accessible to all providers involved in that patient's circle of care - is critical. If time permits, consider proactively calling or arranging virtual visits with your highest risk patients to ask if they are having or have thought about having planning conversations with their loved ones. Explore their goals-of-care if they are open to doing so and document their wishes in the medical record. Many online resources are emerging that can help equip you with language to guide COVID-19 planning discussions (10). A key step in a goals-of-care discussion is making a recommendation, with permission, based on the patient values discussed. This could be a treatment recommendation (e.g., "Based on what you've shared with me today, I would suggest a trial of antibiotics for possible pneumonia and calling our clinic if your cough worsens."). goals-of-care conversations can be iterative, so your recommendation could simply be to schedule a follow-up conversation to further explore patient hopes and worries that will better enable you to tailor values-based treatment recommendations.

Consult palliative care when needed

PC is a medical specialty acting as an added layer of support to patients and families living with serious illness. It is delivered by an interprofessional team, focuses on improving quality of life at any stage of illness, and can be delivered alongside curative treatment (11). If specialist PC services exist in your area, consider consulting them when your goals-of-care conversations lead to a patient or family requesting treatment that you worry may not help them to achieve their goals. PC clinicians may suggest organizing a family meeting, where the patient, family and team of health care providers come together to reassess patient values and goals using a structured

approach to assist in treatment decision-making. PC specialists can spend additional time explaining the philosophy of symptom-focused supportive care for patients that desire quality of life over quantity. During the pandemic you can also consider consultation for patients whom you worry may require complex treatment decisions associated with possible intensive care. Online palliative care tools are essential for in-the-moment skill building and many are freely available (12,13). These tools can be particularly useful for regions without access to specialist PC services, or where these services are unable to respond quickly due to being short staffed or when patient need overwhelms available specialist team resources.

Make communication a part of your preparedness plan

As resources become more limited, it is important to continue to practice compassion not only towards patients and their families, but also towards our clinical teams, institutions and ourselves. Feeling better equipped with communication skills to navigate general and pandemic-related goals-of-care conversations may increase clinician confidence and the ability to provide sustainable care during this unprecedented time. Moreover, some of the skills described in this article may help health care teams better communicate with each other and this may help teams stay healthy throughout this crisis; a healthy workforce is essential in order to be able to provide high quality care to during this difficult time.

Case Resolution

Jenny's husband, Frank, was able to connect with his wife's family physician. At the time of the phone call, Jenny remained mildly symptomatic and gave permission for Frank to speak directly with her doctor on her behalf. The family physician's comforting, honest, and clear communication skills decreased anxiety related to the uncertainty Frank was facing. Their conversation highlighting some of the communication skills described in this article is illustrated in Table 2.