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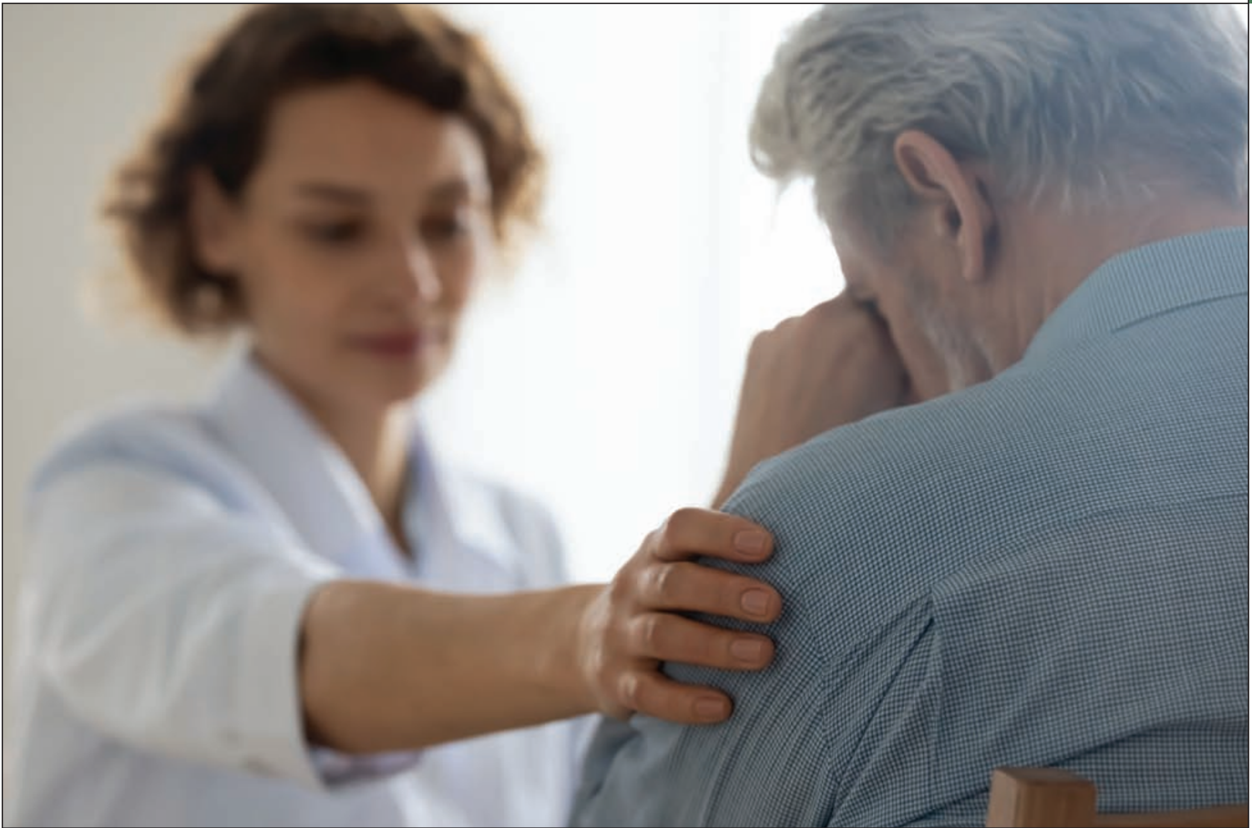

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"What are my options?": How to have a goals-of-care conversation

Abstract: Patients may choose to have a conversation with their providers about their care options. This article presents a guide for NPs for these goals-of-care conversations. NPs having these conversations can follow the strategies presented to plan the discussion, overcome barriers, and offer useful resources and support.

By Melissa Boettger Bartholomew, MSN, BSW, RN, AGPCNP-BC

As you prepare to see your next patient, you remember that the last time you saw them, they were waiting for biopsy results after an abnormal mass was found on computed tomography scan, and you were unsure if the patient would want to pursue aggressive disease-directed treatment if it were malignant. Do you know how to have this discussion? Do you feel comfortable having this conversation? The goal of this article is to help NPs better understand the process of and feel more comfortable having goals-of-care (GoC) conversations by providing information about the reasons for GoC discussions, relevant communication techniques, ways to have these discussions, and associated barriers.

Reasons for GoC conversations

The type of patient who will most likely require a conversation about their GoC is one diagnosed with a life-limiting condition. A life-limiting condition is often incurable and may shorten the patient's lifespan.

Keywords: advance care planning, decision-making, goals of care, palliative care, provider education

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Life-limiting diseases include advanced cancer, congestive heart failure, chronic obstructive pulmonary disease, dementia, neurodegenerative diseases, chronic liver disease, chronic kidney disease, and other similar conditions. In 2019, at least 12 million adults and 400,000 children were living with a serious illness in the US that could be considered life-limiting.[1] Complex, invasive, and technically advanced treatments have become available. However, they are often difficult to understand and potentially burdensome to patients and their families and may not provide meaningful extension of life in all cases.[2] NPs can guide the conversation to help patients consider benefits and burdens of available options and make the choice that best aligns with their values and wishes.

To meet the needs of patients with serious illness, GoC conversations are critical.[3] GoC conversations allow an NP to discuss information related to the disease process, prognosis, treatment options, risks, and benefits, and develop a plan of care. But they can also be intimidating for patients because disagreements can arise among family members or even between the patient and provider regarding the best plan for moving forward. Nonetheless, patients are increasingly choosing NPs as their primary care providers (PCPs) so the ability to lead a GoC conversation is a necessary skill in primary care and many other practice settings. In the following sections, general communication techniques to use when approaching serious conversations will be discussed before a focused introduction to GoC conversations.

Communication

Communication is a key aspect of having a GoC conversation. There are over 290,000 NPs in the US, which suggests that many patients utilize NPs as their PCP.[4] Americans have rated nurses as the most ethical and honest profession for 20 years in a row.[5] As PCPs, being trustworthy and developing a rapport with patients can enable NPs to become the patient's choice to have a GoC conversation. Developing proficiency in communicating about serious illness goals requires training and practice to ensure quality and effectiveness.[6] Important aspects of communication during GoC conversations are listed below.

- Use open-ended questions: Open-ended questions encourage the patient to express more detail.[7] Asking the patient "What is your understanding of your disease process?" is an example.
- Rely on silence: Silence allows information to be processed by the recipient. The patient may find themselves sifting through some challenging thoughts and feelings as they attempt to organize the discussion during this silence.[8] Our society often perceives silence in a conversation as awkward, but in GoC conversations, it is a necessary tool.
- Provide affirmation: Provide positive affirmations throughout the conversation to convey understanding and support. For example, "The team is here to support you and your family."
- Explore concerns: Ask questions to better understand what the patient is saying or to elicit additional information, for example: "I want to make sure I am understanding what you are saying—is it correct you no longer want to return to the hospital for treatment?"
- Employ nonverbal communication: Note that your body language is open and accepting of what the patient is discussing. Show that you are listening to what the patient is saying. Sit close to the patient and at the same level, do not stand over the patient. Utilize therapeutic touch as appropriate.
- Utilize lay terms: Use words the patient can understand instead of medical jargon. Explain terms that need to be used but are not common knowledge. Some examples include saying "spread" instead of "metastasis," "medication" instead of "oral chemotherapy," and "removed with surgery" instead of "resection."

GoC discussion

Preparation is imperative when beginning conversations with patients about GoC. Providers should be aware of important terms utilized during GoC conversations (see *Terms utilized during GoC conversations*). Such conversations usually require more than one visit, with the NP guiding the patient through various options. Allowing time between visits provides patients and their families time to reflect upon the discussion and consider the options.

The first step in preparing to have a GoC conversation is to review the treatment plan presented by the patient's specialist, including their prognosis of the patient's disease process. Determine if alternatives to disease-directed treatments (like comfort-focused care) were discussed. Subsequent steps involve reviewing notes written by the specialist involved in the patient's care, gathering patient education materials on

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the treatments being recommended, identifying whether there is anything you do not know in the treatment plan, and completing any research about options. Make sure the patient is scheduled for adequate time for the conversation and remind yourself that the patient needs your expertise to develop a tailored and individualized plan of care.

When considering the appropriate time to schedule a GoC visit, it is important to know that there are Current Procedural Terminology codes associated with advance care planning (ACP) to allow for billing this type of visit. Refer to the Centers for Medicare and Medicaid Services fact sheet information regarding billing for ACP visits.[13]

Preparing the environment for the conversation is important. A private area is needed for the discussion. Turn off pagers and phones to minimize interruptions. The provider should not appear rushed or give the impression that there is no time to have the conversation. Sitting close and facing the patient conveys a sense of support and caring as does therapeutic touch as appropriate.

Terms utilized during GoC conversations[9-12]

GoC conversations—GoC conversations are discussions about prognosis, treatment options, treatment risks and benefits, and care planning. These conversations help clarify patients' values to guide the plan of care.

Palliative Care—An approach to care with a goal of improving quality of life of patients and their families facing a life-threatening illness, through relief of suffering. Patients can receive palliative care measures and disease-directed treatments at the same time.

Hospice—A comprehensive, holistic program of care and support for terminally ill patients and their families. With hospice care, the focus changes from curative to comfort-focused with an emphasis on pain relief, symptom management, and psychosocial support, and the patient no longer receives disease-directed treatments. Hospice is a part of palliative care that focuses on end-of-life care.

ACP—ACP involves the patient learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know—both their family and healthcare providers—about their preferences.

Conversation approaches

GoC conversations are ideally initiated shortly after diagnosis of a life-limiting condition and revisited throughout care so that the patient and healthcare professionals have a common understanding on how to proceed.[14] All patients react to the news of their prognosis differently. They can appear to be in denial or in shock, they can express anger, and some may cry. Patients who are stunned may show no emotion. Being aware and having the ability to react empathetically to these emotions is important. Support the patient's reaction by providing therapeutic communication, allowing silence to help them process the information, and/or by providing therapeutic touch, as appropriate. Using NURSE statements (naming, understanding, respecting, supporting, and exploring) when responding to patient emotions can be useful for expressing empathy.[15]

GoC conversations should clarify patients' values, goals, and priorities regarding their diagnosis, prognosis, and treatment options.[16] A good way to open the GoC conversation is by asking the patient to describe what they understand about their disease process, prognosis, and/or availability of treatment. Understanding their thought process is important because multiple factors can impact understanding. For example, a patient may say, "my wife's cousin had cancer too and received this chemotherapy, so I will get that treatment too." This statement could be a contradiction to the treatment plan outlined in the specialist note. Identifying the patient's perspective will help lead the discussion. Once the patient's understanding is established, clarify how much and what type of information the patient wants to receive. The NP must ask if the patient would like the full information about their diagnosis and treatment options provided to another individual.

Educate the patient about their disease, focusing on what they do not understand. If the patient has a full and accurate understanding of the diagnosis/prognosis, the conversation can focus on treatment options. If the patient is unsure of or has misunderstandings about the implications of their diagnosis and/or treatment options, the NP can facilitate the conversation accordingly by first helping the patient have a clear understanding of the diagnosis, prognosis, and treatment options so that they can make an informed decision.

Next, discuss what is most valuable and important to the patient while dealing with their disease process. For many patients, preferred GoC will fall within one of the following categories: cure, live longer, improve or maintain function, comfort, achieve life goals, or provide support for family.[15] Patients may make statements about

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A quick guide to GoC conversations for the NP

- Prepare for the conversation by reviewing the patient's chart
- Plan for the possibility of multiple visits to cover all topics
- Sit down and talk with the patient
- Do not appear rushed during the conversation
- Ask the patient what they understand about their diagnosis/prognosis/treatment options
- Educate the patient about their disease and treatment options based on their understanding
- Educate the patient on implications of pursuing and of not pursuing disease-directed care for their diagnosis
- Discuss hospice and when it would be appropriate
- Explain advance directives and assist patient in completing documentation or provide resources to the patient
- Refer to palliative care when available and appropriate
- Summarize the discussion
- Answer any questions
- Document and make appropriate providers aware of the discussion
- Advocate for the patient's wishes

their wishes such as "I do not want to feel sick," "I want to be able to spend time with my family," "I want to complete certain activities," or "I want to live longer." Identify and discuss which specific treatment options may fit best with their values and goals. Framed by a GoC, dialogue about decision-making moves the question from "Would you like us to do this, or not?" to "Will this help us achieve your GoC, or not?"[16] By familiarizing oneself with the topics that commonly arise in GoC discussions, the clinician can build a skill set to successfully navigate and improve the quality and value of such conversations.[9]

At the end of the session, summarize what was discussed and ask if the patient has any questions. The patient may want time to think about all the different options and/or consult with family. Some patients might decide more quickly. Other patients might change their mind multiple times. The role of the NP is to be a listener, document the discussions with the patient, and make appropriate referrals based on the patient's preferences. It is important to recognize that not all decisions may be made in one visit, and multiple visits may be required to have a robust discussion (see *A quick guide to GoC conversations for the NP*). Another important role of the PCP is to advocate for the patient, especially when their choice may conflict with that of the specialist.

One framework the NP may want to consider utilizing to frame the discussion is the 3-Act Model. The 3-Act Model consists of 1) understanding the patient's story, including perspective of the medical situation within the larger personal narrative with sensitivity to language and values; 2) discussing medical opinions in simple language and big-picture terms; and 3) making shared decisions within the context of patient's story, language, values, and receptivity. Other key elements are the prologue (preparing beforehand, including clarifying issues and options and establishing rapport) and the epilogue (concluding the meeting and coordinating afterward.[17]

GoC discussions are an integral part of, but not synonymous with, ACP.[18] If ACP is a topic the NP has previously not discussed with the patient, now is a good time to have this discussion. The ACP process enables adults of any age or at any stage of health to understand and share their personal values and life goals, and outline their preferences for future medical care. ACP allows individuals to receive medical care in accordance with their values, goals, and preferences in the case of serious and chronic illnesses.[19] ACP and GoC conversations are important to understand and incorporate into regular practice. The resources provided in this article can assist in completing an ACP conversation.

A referral to palliative care may be appropriate for select patients, regardless of whether or not the patient chooses to pursue disease-directed treatment. Palliative care can provide support through disease-directed treatment and also if comfort is the primary goal.

Barriers to conversation

There will be barriers to GoC conversations. These barriers may be presented by patients, providers, or families. Each one of these challenges will be discussed in the following section.

Patient. One potential barrier to GoC conversations is a patient's difficultly in understanding or accepting their prognosis and the options related to their prognosis. In a study that identified oncologist-perceived barriers, the ability of patient and families to understand and accept the nature of their disease was ranked as highly important.[20] As an NP, helping the patient to understand this information in simple terms is important. Even though a patient may thoroughly understand their prognosis and the options available, they may be in denial, indecisive regarding treatment

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decisions, or unwilling to discuss their prognosis. Continuing conversations at the patient's level and allowing the patient time to process is important to overcome these barriers.

If it is suspected that a patient might not have decision-making capability, an evaluation for capacity should be completed.[21] A patient that does not have medical decision-making capacity and has not previously identified a surrogate decision-maker via an advance directive can present another barrier. If a surrogate decision-maker hasn't been designated, following state guidelines for who is to be recognized as default decision-maker is essential. Once it is clear who the decision-maker is, the NP should complete the GoC conversation with this individual. Despite being designated as the default decision-maker per state guidelines, some family/friends may not be willing or able to take on the responsibility of decision-making. Consulting state guidelines on who would be designated as next-in-line as decision-maker, the NP may need to continue to contact family/friends until an appropriate and willing individual is identified.

Providers. A PCP might not agree with a patient's choice to obtain or refrain from disease-directed treatment. Self-reflection can raise awareness of personal beliefs regarding treatment decisions. When there is a conflict in values, the NP must recognize the mismatch and determine if it would be better to ask another member of the care team to lead the conversation with the patient and family. A lack of knowledge of healthcare professionals regarding the differences between palliative care and hospice or the belief that palliative care is unnecessary for patients who are not considered terminally ill can also be a barrier.[22] Providers may be uncomfortable discussing death and dying. Practicing these discussions can decrease discomfort and improve time management.

Other providers such as specialists who are involved in the patient's care could also pose potential barriers. Although perspectives on curative treatments are shifting in favor of more holistic and patient-oriented models, some providers feel that stopping curative treatments, even when it is the patient's choice, is a failure. If a provider disagrees with a patient's choice and is unable to participate neutrally in a GoC discussion, the ability to ask another provider to lead the conversation is essential. Alternatively, if a provider feels confident initiating this conversation, they should meet with the patient and family as needed.

Families. Family dynamics can underlie many barriers to effective GoC conversations. For example, it can be challenging for family members to think about their loved one stopping or not accepting treatment; in some cases, foregoing treatment may be considered a "death sentence." Family members may have unrealistic expectations of treatments which may lead them to pressure the patient into continuing disease-directed care. A study found that difficulty accepting poor prognosis and understanding the limitations and complications of life-sustaining treatments as well as conflicting goals were perceived by healthcare professionals as barriers for families.[23] Including the family in GoC conversations, with the patient or surrogate decision-maker's permission, can help work through differences and provide education on diagnosis/prognosis and the patient's wishes.

Continuing conversations at the patient's level and allowing the patient time to process is important to overcome barriers.

Other barriers exist aside from those presented here. However, NPs should consider the individual patient and potential barriers. Determining ways to overcome these barriers will improve the GoC conversation.

Provider resources

NPs need to be informed of available resources to assist with GoC conversations. They also need access to resources to share with the patient and/or family. Some resources that may help NPs understand GoC conversations and decisions for these patients are listed below.

- Five Wishes is a document that assists with ACP. It is available at fivewishes.org, and many palliative care teams and/or case management departments may have them available for patients. This document is easy to read and understand. It allows the patient to work through decisions about their care in terms that are easy to understand. Forty-six states accept

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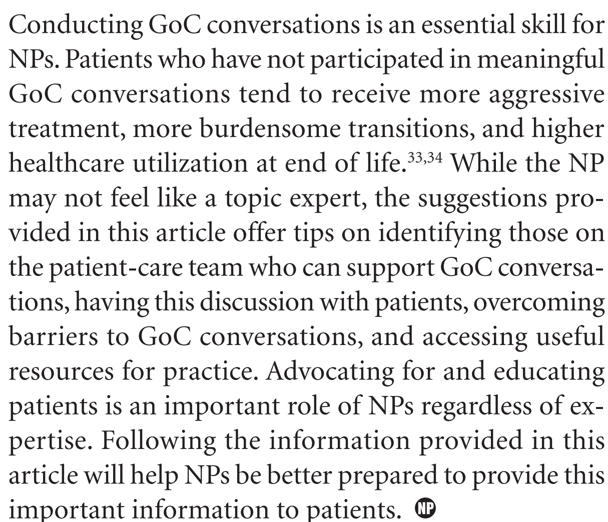
this as an advance directive. Most states accept it as a legal document once it is signed by two witnesses who do not have a conflict of interest (such as those listed as the patient's decision-makers or who are the patient's healthcare providers). Some states require notarization of the document.[24]

- POLST forms provide medical orders for specific treatments during emergencies and are completed by a patient or surrogate decision-maker together with a provider.[25] Thy are specifically intended for patients who are seriously ill or have life-limiting conditions. The forms usually have sections addressing CPR, initial treatment (full, selective, or comfort-focused), and medically assisted nutrition.[26] POLST programs are run by the states; the specific form for the individual state should be used. Each state may call the form by a different name.[27] You can see what the form is called in your state here: https://polst.org/program-names/. The national POLST organization provides an overview/education regarding the form purpose, with an initiative to have all states utilizing the national POLST form. Currently only a few states have adopted the national POLST form or adapted the state's form from it.[26] The forms can usually be obtained from state health departments.
- The "5 D's" is a useful tool from the American Bar Association Commission on Law and Aging that provides recommendations on when a patient's advance directive should be reviewed for changes or updates.[28] The guide can be accessed at: www.aaepa.com/2012/09/5-ds-reviewing-clients-advance-directives/.
- ePrognosis is a website that provides a repository of published geriatric prognostic indices for providers to obtain evidence-based information about a patient's prognosis. It also has a page dedicated to communication including GoC.[29] The site can be accessed at https://eprognosis.ucsf.edu/.
- VitalTalk has a website and app that provide evidence-based research on serious illness communication. The site provides tips as well as courses to educate healthcare professionals and is at www.vitaltalk.org/.[15]
- The Serious Illness Conversation Guide created by Ariadne Labs provides a guide for the conversation and appropriate wording to use during the conversation.[30] The guide can be accessed at www.ariadnelabs.org/serious-illness-conversation-guide-training/.
- Respecting Choices® is an evidence-based system for ACP that creates a healthcare culture of person-centered care.[31] The website is https://respectingchoices.org/.

Patient resources

- Prepare for Your Care is a free website that educates patients on having conversations about their advance directives and allows them to complete an advance directive.[32] Direct patients to https://prepareforyourcare.org/welcome.
- The Conversation Project provides a free kit for patients to have conversations about their end-of-life care.[33] The kit can be found at https://theconversationproject.org/.



Conclusion

Conducting GoC conversations is an essential skill for NPs. Patients who have not participated in meaningful GoC conversations tend to receive more aggressive treatment, more burdensome transitions, and higher healthcare utilization at end of life.[33,34] While the NP may not feel like a topic expert, the suggestions provided in this article offer tips on identifying those on the patient-care team who can support GoC conversations, having this discussion with patients, overcoming barriers to GoC conversations, and accessing useful resources for practice. Advocating for and educating patients is an important role of NPs regardless of expertise. Following the information provided in this article will help NPs be better prepared to provide this important information to patients.

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Melissa Boettger Bartholomew is a full-time nursing instructor at DeSales University. She continues to practice as a hospice nurse practitioner. She is also a PhD candidate at Indiana University of Pennsylvania.

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