CCSEO Guideline

Goals of Care, Advance Care Planning, and Referral to Palliative Care

This guideline addresses the following issues:

1. Discussions regarding goals of care and advance care planning
2. Referral to Palliative Care

PREAMBLE

An understanding of patients' goals of care in the context of a serious illness is an essential element of high quality care. This enables the clinician to align the care that is provided with what is most important to the patient. Early discussions are associated with improved quality of life (QOL), decreased use of non-beneficial medical care as persons approach the end of life, improved care consistent with patient goals, greater family satisfaction and decreased costs to the health care system (Bernacki RE, Block SD; JAMA Intern Med. 2014; 174(12)).

Best practices in discussing goals of care include (Bernacki RE, Block SD; JAMA Intern Med. 2014; 174(12) and You JJ, Dodek P et al; CMAJ, Dec 9/2014, 186(18)):

1) Sharing prognostic information,

2) Understanding patient fears and goals,

3) Determining preferences for decision making,

4) Understanding patient perspectives regarding what is acceptable to them in terms of their functional abilities (what is tolerable), what are they willing to accept as "trade-offs" to achieve different outcomes,

5) Ensuring family members are involved and understand the patient goals and preferences

Early and effective communication about goals, prognosis, and care options can improve medical care of patients throughout the illness trajectory by ensuring that the treatment they receive matches their wishes.

The integration of palliative care earlier in the illness journey is associated with more co-ordinated care, lower rates of depression and anxiety, greater caregiver satisfaction, decreased pain, higher QOL and an increased likelihood of patients dying in their place of choice (Temel JS, Greer JA et al; N Engl J Med. 2010;363 (8)).

DEFINITIONS

Advance Care Planning (ACP) is a communication process involving reflection, deliberation and determination, wherein a capable person discusses their values, wishes and preferences with their substitute decision maker (SDM) and /or member of the health care team, to prepare for future decisions or in the event that the patient cannot make decisions for him/herself. Part of this process involves designating a trusted individual (Substitute Decision Maker, Power of Attorney for Personal Care) to make care decisions on their behalf when they are no longer capable, that align with their wishes and values (Sinuff T, Dodek P, You JJ et al; JPSM Vol 49, No.6, June 2015).

Goals of Care Discussions (GOCD) is also a communication process between a physician, patient, and/or SDM that is governed by informed consent and results in medical decisions within a plan of care. Elements of these discussions include (Sinuff T, Dodek P, You JJ et al; JPSM Vol 49, No.6, June 2015):

- The patient/family understanding of the illness;
- Whether the disease is curable, incurable or chronic;
- What is the illness trajectory and prognosis;

- What are possible outcomes of proposed treatment options, including QOL;
- The expression of a person's values and what has meaning for him/her in the current context of care;
- Understanding patient fears or concerns;
- The thresholds of the disease or symptoms, from the patient/family perspective, that may inform changes in the goals of care;
- Recommendations from the health care provider/team regarding potential benefit and/or harm of life-sustaining treatments/resuscitative measures;
- Ensuring medical decisions regarding care are clinically indicated and align with the patient's goals for their care;
- Prompting and addressing questions raised by the patient/family

Documentation of these discussions and plans must be present across time and place in the health care system.

CCSEO GUIDELINE RECOMMENDATIONS

It is recommended that all members of the health care team at CCSEO will identify individuals that could benefit from GOC discussions, ACP discussions and referral to palliative care.

Recommendations for Referral to Palliative Care and/or ACP/GOC Discussions

Patient parameters	Palliative Care Referral?	GOC and ACP discussion?	Comment
Patients with complex symptom burden from **cancer and/or treatment-related toxicity**, with symptom severity scores >4/10 that persist for more than three visits.	Yes	To be considered based on other prognostic parameters	Not all patients with complex symptom burden are in the late/incurable phases of their disease, but all patients will benefit from Palliative Care referral.
Patients whose physician answered "no" to the following question: **"Would you be surprised if this patient died within the next 12 months?"**	Yes	Yes	GOC and ACP discussions may not require Palliative Care referral; they may be done by oncologists and documented appropriately in the patient chart. It is recommended that these are dynamic discussions such that specific elements will need to be readdressed depending on

			changes in the health care status of the patient.
Patients with general indicators of decline: such as • Decreasing activity, declining performance status (PPS<60 %) • Increasing support needs • Advanced progressive incurable disease with complex symptom burden • Declining response to treatments, decreasing reversibility of disease process • Multiple unplanned or crisis hospital admissions	Yes	Yes	GOC and ACP discussions should be coordinated between the palliative care MD and the oncology MRP if the patient is still receiving disease directed therapies.

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May 4, 2016