New Diagnosis Bundle: Improving Care Delivery for Patients With Newly Diagnosed Cancer

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A new cancer diagnosis is almost universally disorienting and frightening. It therefore is not surprising that anxiety and depression are highly prevalent among newly diagnosed patients1 and that the need for cancer care (a high-emotion service2) can lead to fear, sadness, and helplessness.2 Although a cancer diagnosis is not always life ending, it is a life-changing event that triggers an array of often-unmet psychosocial, informational, and physical needs.2-4 The level of unmet needs for older patients with cancer, for example, is highest soon after diagnosis and when treatment starts, then decreases over time.3 The critical period right after patients learn that they have cancer deserves much more attention than it currently receives.

Post-Diagnosis Shortfalls

Across the age spectrum, patients with newly diagnosed cancer frequently cite inadequate information as a key stressor for themselves and their families.3,4 Misunderstanding of diagnoses and treatment goals is also a prevalent issue. Indeed, in a 2008 study of patients newly diagnosed with lung cancer, physician and patient recall of information was not fully congruent 43% of the time for discussions about diagnosis and 66% of the time for discussions about treatment goals.5 Similarly, in a study of patients with newly diagnosed metastatic disease, 69% and 81% of people with lung and colorectal cancer, respectively, did not understand that chemotherapy was unlikely to cure their conditions.6 Clinicians may not convey all of the pertinent information clearly, at the right pace, at the right time, in the right setting, or with sufficient balance and sensitivity. Cognitive and emotional strains also can limit the ability of patients to absorb information.

Frustrations with care systems are also common. Patients with newly diagnosed cancer report dissatisfaction with delays in diagnosis and follow-up.2 Studies have demonstrated that patients waiting for cancer-related surgery experience impaired quality of life,7 and that prolonged wait times raise significant concerns for patients with cancer.8 Although care coordination is recognized as a priority, fragmentation of care persists, because many health professionals work in isolation rather than in synchrony, and patients are left to navigate unclear communication streams and confusing systems.9 Our experiences treating patients with cancer (J.O.J.), serving on their care teams (L.S.R.), and interviewing them (L.L.B.) have revealed this obvious, yet often overlooked, truth: after a diagnosis as devastating as cancer, patients find inaction and inefficiency in the systems that are supposed to care for them simply intolerable.

Finally, psychosocial concerns—including uncertainty about mortality, why cancer developed, body image, relationships and family, finances, work plans, and control
A Care Bundle for Newly Diagnosed Patients

We propose that the experience of patients with newly diagnosed cancer should begin with a care bundle that, though individualized, includes a standard set of high-quality, efficiently delivered services. This bundle would have value for all newly diagnosed patients, especially for those with complex needs, such as those with locally advanced cancers that require multimodal treatment, metastatic cancers, cancers treated with high-risk or toxic therapies, cancers with competing or controversial treatment options, or cancer accompanied by significant comorbidities.

The bundle should adhere to these five principles:

1. Understand the patient medically and personally, including cultural beliefs, decision-making style, family support, living conditions, and financial situation.
2. Create a structured treatment plan that is informed by multidisciplinary participants and a patient’s unique needs, that summarizes pertinent test results and a course of action, and that is accessible to both patients and providers.
3. Time educational efforts appropriately, by incorporating input from the patient and the family about what they want to know and their level of comprehension.
4. Help the patient and family maintain control over their lives and manage their emotional reactions.
5. Minimize anxiety related to needless waiting for information or next steps.

To deliver on those principles, timeliness is essential not only for minimizing the patient’s and family’s anxiety but also for establishing an expectation of efficiency for the care team. We recommend a 10-day window for delivering the care bundle. Why 10 days? First, a poorly demarcated standard is not really a standard and, thus, is unlikely to change habitual processes and behaviors. Second, with concerted effort and a collaborative commitment, a 10-day window is an achievable goal in most cases. Even when additional testing is necessary beyond the 10-day window, the ability to say “this is what we know so far” can offer immense emotional benefits to the patient and family.

We have organized the standard elements of the 10-day care bundle into four categories (the four Ts):

**The Team**
- Identify the members of the multidisciplinary care team, and make each member’s role explicit.
- Appoint a patient coordinator or navigator to assist the patient and family both proactively and reactively before and during the treatment course.
- Delineate the primary care physician’s role in the patient’s cancer care.
- Have the patient choose family and friends to be in his or her inner circle, and encourage their involvement.

**The Timing**
- Condense all of the patient’s appointments related to diagnosis, assessment, and creation and communication of a treatment plan within the 10-day window.
- Designate a physician or service that is responsible for organizing and scheduling diagnostic and staging studies, coordinating specialist evaluations, and closing communication loops.
- Phase in information and educational services, rather than frontloading them into the initial appointment.
- Time meetings with social workers, behavioral specialists, financial counselors, and other support staff to optimize the value of their input.

**The Treatment Plan**
- Assemble all relevant clinical data necessary to fully inform the diagnosis and prognosis and to arrive at the best available treatment option.
- Document that all key data have been reviewed by all relevant clinicians, who then each approve the treatment recommendation.
- Ensure that the treatment plan includes the patient’s care goals, a psychosocial assessment, and an assessment of the patient’s support system (including financial needs).
- Communicate the treatment plan in a calm, comfortable setting where the patient’s and family’s questions can be answered without hurry.
- Provide the patient with a customized version of the treatment plan that succinctly describes the diagnostic and staging details, the prognosis, the goals of treatment, and the sequence and expected timing of each phase of treatment.
- Ensure that all relevant providers can access the treatment plan.
The Tools

- Give the patient and caregivers information in multiple formats: shared decision-making aids, written take-home notes, videos, customized information packets. Materials should be given in either paper or electronic format, as the patient desires.
- Use teach-back techniques to ensure that the patient accurately comprehends all pertinent information.
- Provide the patient with a list of credible internet sources about his or her condition.
- Specify which professionals the patient should contact with particular types of follow-up questions.

We acknowledge that systemic factors may in some cases stand as challenges to the implementation of our proposed bundle. Prevalent reimbursement models do not support the costs associated with financial counselors, patient navigators, or social workers. Similarly, shared decision-making and teach-back techniques, although highly patient-centered, require time and training and, thus, may feel unrealistic for some small practices. In the short term, we encourage practices to capitalize upon the diversity of high-quality patient navigation, care coordination, and joint decision-making resources that are publicly available to enhance the capabilities of their existing care teams.10-14 In the longer term, we are hopeful that new reimbursement models, such as the episode-based Oncology Care Model by the Centers for Medicare and Medicaid Services9,15 will increasingly provide the right incentives and structure for delivering individualized team-based care at the time of diagnosis.

We believe our care bundle proposal has the potential to streamline the cancer-care continuum for patients and families during a period of medical crisis and emotional vulnerability, when the need for timely, well-coordinated service is considerable. The impact of the proposal will be greatest if it is customized, as necessary, within the basic framework; accompanied by appropriate financial incentives; supported by relevant, integrated health information technology solutions and creative multidisciplinary coordination mechanisms; rigorously evaluated to measure its value overall and the value of its components; and updated and improved as needed. JOP

Authors’ Disclosures of Potential Conflicts of Interest

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Author Contributions

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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