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Attachment 14

Assessing Problem Areas in Referrals for Chronic Hematologic Malignancies and Developing Interventions to Address Them

Primary Care Providers Focus Group Guide (draft)

HSC-SPH-07-0187

PRIMARY CARE PROVIDERS PROTOCOL A - FOCUS GROUP GUIDE

Introduction:
We are exploring patient and provider experiences with chronic hematologic malignancies such as chronic lymphocyte leukemia, multiple myeloma, chronic myelogenous leukemia (CML) and myelodysplastic syndrome. We are particularly interested in understanding whether or not there are problems with any processes of patient care or delays in diagnosis and treatment. As you may know, there have been treatment developments for some of these cancers that make decreasing delay important. We would very much like you perspective on this issue. We will try to understand from you some specific considerations related to hematologic malignancies such as what factors or scenarios lead a physician to recognize a patient with a malignancy, consult another physician, make a referral, and/or diagnose a chronic hematologic malignancy. We are hoping to understand from you whether and how these processes can be problematic.

We are going to run the focus group a little differently from what you might be used to. I am going to guide the discussion with a series of questions. In addition to tape recording the answers, X and X will serve as notetakers. They will note your responses and post theme on the white paper posted on the walls. If we have a few minutes at the end, we will see if we can organize any themes regarding problems from the responses on the walls.

1. To get right to the issue of whether or not there are problems – Can you think of a patient or a situation in your experience or the experience of a colleague – where the diagnosis or care of a patient with a chronic hematologic malignancy was problematic.

Probes:
What about with diagnosis?
Getting treatment? Referral? Consultation?
What were the specific problems?

2. I would like to read you part of a case. What do you think most primary care physicians would do in this situation. Ready?
A 50 year old woman presents with several weeks of fatigue and a 2.5 cm mobile mass in her cervical chain that she associates with an upper respiratory syndrome. She is otherwise well-appearing. This is her first visit for this complaint. Her CBC is normal except that her white cells are slightly elevated (12.5) with 85% lymphocytes.

So what would most physicians do?
Probes: Anything else? (Until conversation seems exhausted)

Ok, the case continues. Ready?

The woman is given three days of azithromycin and scheduled for follow-up in two weeks. She cancels because of a work conference and reschedules for one month later (six weeks from her last visit). At that appointment, she says the mass is smaller; however, on exam, it seems

unchanged. She otherwise feels well, but you find a .5 cm "shotty" groin node on exam. A repeat CBC shows mild anemia (33.5%), normal platelets, and white cells are now 14.8 with 83% lymphocytes.

What would most physicians do?
Probes: Anything else? (Until conversation seems exhausted)
What about others in the group? Anything that you would do different from what has been discussed?

3. Thinking about patients in your practice, what factors have made you suspicious of a chronic hematologic malignancy?

Probes: What signs, symptoms, or lab results lead you to consider this possibility of a chronic hematologic malignancy? How often have you seen these kinds of patients?

4. Think about a recent patient; please describe what you did after you first had suspicions about a chronic hematologic malignancy. What were your next steps?

Probes:

- Did you seek additional information? Where?
- Did you consult another physician? Was this an informal or formal consultation?
- Did you refer the patient? If so, to whom did you refer the patient?
- What did you consider to make these decisions about consultation and/or referral? What other factors might be important in these decisions?
- Did you diagnosis this patient?
- Did you treat this patient?
- Was this a fairly usual situation?

5. How do you think the experiences you just described are similar or different among your colleagues?

6. Are there times when you don't consult a specialist or refer a patient with the kinds of problems you have been talking about? Why or Why not?

7. Overall, what are the most important factors that affect your decision to refer a patient to a specialist?

Probes:

- Organizational practices?
- Guidelines?
- Internal system?
- Paperwork, staff, etc.?
- Insurance?
- Experience?
- Research resources or opportunities for clinical trials?

8. Thinking about the last referral you made regarding a chronic hematologic malignancy, what was your experience in making this referral?

Probes:

- Were there any problems? If so, why?
- Was it easy? If so, why?

If these topics have not been covered in the previous questions, the following questions can serve as further probes.

9. What do you think works well when...
    - Diagnosing a chronic hematologic malignancy?
    - Referring a patient with a chronic hematologic malignancy to a specialist?
    - Identifying the possibility of a chronic hematologic malignancy?
    - Can you think of anything that could work better, faster, smoother, easier, etc.?

10. How do you know if (when) a patient has seen a specialist after you've requested it?
    - Have you ever been aware if a referral does not occur as you thought it would?
    - What type of feedback would you prefer from the specialist?
        - Email, phone call, letters, etc.?
    - What kind of systems might better ensure a referral was completed?

11. What improvements could help primary care physicians like you diagnosis and manage patients with blood abnormalities?
    Probes: What would you need...
    - To make managing this type of patient go better?
    - To make it easier for primary care physicians to identify a possible malignancy?
    - To make the necessary referral?