When Hope Is All There Is Left

HANNEKE W.M. VAN LAARHOVEN,^a CARLO J.W. LEGET,^b WINETTE T.A. VAN DER GRAAF^a

^aDepartment of Medical Oncology, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands; ^bFaculty of Humanities, Tilburg University, Tilburg, The Netherlands

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She was an experienced patient, this 54-year-old woman I saw in my outpatient clinic. Thirteen years before, Mrs. B. had been treated with cyclophosphamide, doxorubicin, vincristine, and prednisolone (CHOP) because of a non-Hodgkin lymphoma (NHL) stage IVB, resulting in a complete remission. Now she was diagnosed with multiple pulmonary metastases of a Ewing sarcoma of unknown primary origin. Moreover, a new bone marrow biopsy showed recurrence of the NHL. Although the CT images of thorax were clouded with metastases, she had no complaints, except for a mild cough and grade 1 neuropathy as a result of the previous treatment with CHOP.

What did I have to offer her? At her first visit, Mrs. B. wanted to know the ins and outs of all treatment options. She was an intelligent woman, enjoying life in all its dimensions. We discussed the impossibility to cure the disease and the hope that palliative chemotherapy could improve life expectancy, however, at the costs of side effects. It was a hard decision for her, but the will to live outweighed her fear for side effects and hospital admissions. We started treatment with etoposide, cisplatin, and ifosfamide. After four cycles, a partial response on computed tomography (CT) and a complete metabolic response on FDG-PET (fluorodeoxyglucose-positron emission tomography) was

observed, and after six cycles, response on CT was still ongoing. However, the treatment was complicated by severe nausea and vomiting during the first cycle, requiring dose reduction. During subsequent cycles she was admitted to the hospital because of fever and pneumonia and in the course of time her neuropathy worsened. In fact, after the seventh cycle we had to stop treatment because of severe, grade 3, neuropathy. Unfortunately, already 3 months later some progression was noted on the CT scan, which was unmistakable another 10 weeks later.

Did I still have something to offer her? Second-line chemotherapy? Topotecan with cyclophosphamide? Oxaliplatin with cyclophosphamide? Something else? And if we treated her, what were we hoping for? Of course, extension of her life. But at what price and for how long? Nobody knew for sure, but looking at our experience during first-line treatment, it was reasonable to expect that the side effects would be considerable and that the benefit of the treatment, if any, would probably not last long after termination of treatment. We had a long and intense discussion about the pros and cons of second-line chemotherapy. Mrs. B. decided that at this very moment she did not want the chemotherapy, as she was feeling well right now, but she did not want to make a definitive choice against chemo-

Correspondence: Hanneke W.M. van Laarhoven, M.D., Department of Medical Oncology, Radboud University Nijmegen Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands. Telephone: +31 24 461 03 53; Fax: +31 24 354 07 88; e-mail: h.vanlaarhoven@onco.umcn.nl Received March 10, 2010; accepted for publication March 9, 2011; first published online in *The Oncologist Express* on May 31, 2011. ©AlphaMed Press 1083-7159/2011/\$30.00/0 doi: 10.1634/theoncologist.2010-0064

therapy either. Therefore, 6 weeks later we had a new appointment. We went over the case for and against chemotherapy again. A decision seemed impossible: the option for chemotherapy with its possible side effects and the hospital admissions frightened her too much to consent, but the option to refrain from chemotherapy with the knowledge that the tumor would progress and end her life frightened her just as much. Again, we made a new appointment 6 weeks later.

Why were we actually making this new appointment? We had gone over all arguments. What else was there to say? I thought I had nothing more to offer her. Every time when we discussed the issue of chemotherapy, Mrs. B. was struggling with the decision, not knowing what to do. It seemed to me that these discussions were not helping her any further. In fact, they made her sad and upset. Therefore, during the next visit I proposed that we would not make a regular appointment for another visit, but that she could contact me any moment she had complaints or wanted to talk to me. She was astonished. This was not at all what she had expected and this was not at all what she wanted. Her eyes filled with tears. Why was that? What had I missed? And then, suddenly, I realized why we were making these appointments: she was hoping for a confirmation that, despite the progression, there was still time, at least 6 weeks. At least another 6 weeks that we could delay the decision, delay the chemotherapy. And then again 6 weeks of delay and again and again and again.... I asked her if my hypothesis was right. She paused for a moment and then she nodded. The discussion about chemotherapy was the formal reason for the visit, but underneath this medical discussion there was the hope, the hope that there was still time, the hope that was kept alive by making an appointment for a next visit. As she said, "At the very moment I would explicitly make a decision against chemotherapy, it would become certain: I will die of this disease."

I hesitated. How to proceed? Of course I didn't mind making a new appointment and participating in this play of hope, as long as we both knew that we were playing and that I did not have the timetable of life at my disposal. However, by making explicit the reason of the visits, we had broken the spell. We agreed that she would go home now and contact me later.

A week afterward, her general practitioner phoned me: Mrs. B. had been admitted to a regional hospital in her neighborhood because of severe dyspnea. A chest x-ray had shown a pleural exsudate, which had been drained by the pulmonary physician. However, after removal of the drain, she had suddenly deteriorated. Mrs. B. died 2 weeks after her last visit to see me.

REFLECTIONS

Living in the age of informed consent, it seems only natural to offer patients full disclosure. Of course, at her first visit when she wanted to know the ins and outs of all treatment options, I discussed with Mrs. B. all that I could think of. Is that not what respect for autonomy is all about? Presenting patients a clear overview of all options, attuned to their level of understanding, so that they are able to make a well-reasoned and justified choice [1]? Although I had done all this, at the end it seemed as if it had not worked out for Mrs. B. Why was that? I began to ask myself: from the very beginning, had I really understood what she had asked of me?

I remember well our first conversation and her wish, like we see in other patients [2], to know all possible treatment options. The same occurred when we discussed second-line treatment. In the light of what had happened afterward, I realized that possibly there also had been other motives accompanying her open and proactive attitude. Did she really want to know all that could be done? Did she really ask me to give a small lecture of possible options? I still think she did. But perhaps she also wanted to show to me that she was a courageous woman, capable of making important decisions by herself. Or perhaps, being an experienced patient, this was the role she thought that was hers to play in this serious condition: being a strong, autonomous, and self-confident patient. However, what was the role I had to play?

Only after having experienced her disappointment when we did not make a next appointment, I realized that, although driven by beneficence, my proposal implied a fundamental change in our clinical relationship. Without realizing it, I had shifted all initiative to her side. Certainly, she was strong, but shifting all initiative to her side was not what she needed from me. She must have felt abandoned for a moment.

Looking back at the conversations in which Mrs. B. did not succeed in making up her mind, I am forced to conclude that I had lost sight of the importance of the process to her. Surely, from my perspective it did not seem to lead anywhere, going over and over all arguments again. However, from her perspective these had been important moments of being taken seriously, being in contact with a physician that cared and had been patiently continued to do so. Moreover, as long as she had not made a choice, in her mind the future would be open, at least more or less. She knew that the more she postponed the decision, the more she was heading toward a situation where no room for a decision would be left at all. However, as long as she did not take the formal decision to refrain from chemotherapy, the final verdict "the last phase of your life has started now" was not brought. In principle, different scenarios would still be possible.

Instead of confronting her with the underlying reasons of her visits, had it been better to continue with this unclear and fuzzy situation? By making things explicit, I had broken the spell that gave her hope. Was this clarity really good care [3, 4]? Or was it rather giving in to my own need, being the kind of person that always tries to seek for clearness, and being a physician that was trained even more to strive for clarity?

Perhaps Mrs. B. was right, even in the way in which she had not come to a clear decision. For how unusual is it to live that way? Looking at the way people make decisions in their lives, there are numerous cases in which people continue to postpone a decision and live in a worrisome condition without making a choice. Think of all the people who, fully competent, continue to live in a dreadful marriage, earn their money under degrading working conditions, or do not go to the doctor although they suspect to carry a serious disease. It could well be that we expect patients too much to conform their ways of making choices to the way we physicians are taught to proceed: rationally, well-documented, and evidence-based.

And what for? Behind our way of operating seems to be the idea that it is a good thing to be open about a terminal condition because this enables patients to prepare themselves for leaving this world [5]. However, what might be a general picture fitting to the (abstract) patient might be far from what this (concrete) patient asks of me. There are people who do not want to give death the smallest place in their life, not even by thinking about it [6]. They cling to life, are focused just on the next few weeks, and postpone the acceptance of their mortality against all odds. Do we really have to disturb that? Maybe we should for some, or even for many patients, or perhaps for the sake of their families and

friends [7]. However, for other patients it may be better to let them live their last weeks of life without making clear decisions and end-of-life preparations, as this way of living and dying is precisely the way they want to leave this world, in conformity with the way they have always lived.

Mrs. B. is one of those patients that I will continue to carry with me. She has taught me an important lesson about listening and caring. Or perhaps, even more important, about the importance of hope as a force that helps to carry the unbearable. What would I do if I had the chance to do it all over? I would try not to take away her hope [8]. I would confirm her idea that there are different possible scenarios in our lives. The fact that some scenarios impose themselves more and more—and they do, by the time passing by—does not mean that there is nothing more to hope for. And I would try to shift gears in my follow-up consultations: I would try to leave behind the discussion about new treatment options, but rather ask her what it meant for her to postpone her decision, inviting her to speak about her hopes for the future and the good things that inspired her to continue to live. In this way I would acknowledge that we, as medical oncologists, have a role beyond offering new treatments to patients with incurable disease: the role of supporter, and of witness. A role that implies that we can and should support a patient, especially in the last stages of illness, when hope is all there is left.

AUTHOR CONTRIBUTIONS

Conception/Design: Hanneke W.M. van Laarhoven, Carlo Leget

Data analysis and interpretation: Hanneke W.M. van Laarhoven, Carlo Leget

Manuscript writing: Hanneke W.M. van Laarhoven, Carlo Leget, Winette van der Graaf

Final approval of manuscript: Hanneke W.M. van Laarhoven, Carlo Leget, Winette van der Graaf

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