

“When patients and families feel abandoned”

Daniel E. Epner · Vinod Ravi · Walter F. Baile

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Abstract

Purpose Patients with serious illness derive a sense of security by forming strong, healing relationships with their providers. These bonds are particularly strong in life-threatening illnesses, such as cancer, which carry the stigma of death and suffering. These strong relationships create expectations in patients that are not necessarily shared by their clinicians. Providers often focus on treating disease and emphasize technically excellent, “evidence-based” practice while failing to fully appreciate the power of the patient–provider relationship. In contrast, vulnerable patients expect much more than technical competence, including open and clear communication, security, continuity, and access. Patients are often left feeling abandoned when their providers do not meet their expectations, even when their care is technically sound.

Methods/results In this paper, we describe scenarios that can lead to feelings of abandonment and discuss strategies to avoid and respond to them.

Conclusions These strategies can help us maintain healing relationships with our patients by maintaining their trust, confidence, and satisfaction. Cultivating relational aspects of medical practice requires an interchange and takes time. Experienced doctors know this and continue to do so because being present and staying with the patient during difficult times is a pillar of moral and ethical training and a fundamental attribute of a good physician.

Keywords Physician–patient relations · Provider · Communication

The case

Mrs. B is a 40-year-old woman with non-Hodgkin’s lymphoma treated by Dr. T for the past 2 years. She was referred for allogeneic transplant after entering remission following salvage chemotherapy. The transplant service evaluated Mrs. B. and deemed her appropriate for transplant, but they told her it would take several weeks to find a donor. While waiting for a donor to be identified, she developed a persistent low-grade fever and rash, which caused her to become anxious and concerned that she would be removed from the transplant list. She therefore sought evaluation in a lymphoma clinic, but they explained that her care was transferred to the transplant team and that she needed to contact them for an appointment. Mrs. B felt puzzled and somewhat deserted by this refusal of care since she had a long relationship with her lymphoma team. “I have known Dr. T for years and he knows me better than any other doctor. His nurse tells me that he can’t see me because my care is transferred to the transplant team. I don’t understand this”. Mrs. B may have felt reassured by a brief conversation with Dr. T. However, Dr. T was unaware of Mrs. B’s predicament since the highly efficient triage system

D. E. Epner (✉)
Department of General Oncology, MD Anderson Cancer Center,
Unit 410, 1515 Holcombe Blvd.,
Houston, TX 77030, USA
e-mail: depner@mdanderson.org

V. Ravi
Department of Sarcoma Medical Oncology, MD Anderson Cancer
Center,
Unit 450, 1515 Holcombe Blvd.,
Houston, TX 77030, USA

W. F. Baile
Department of Behavioral Science, MD Anderson Cancer
Center,
Unit 135, 1515 Holcombe Blvd.,
Houston, TX 77030, USA

in place stipulated that nurses only call a physician for urgent or unusual matters. Mrs. B therefore felt even more anxious after contacting the lymphoma staff than she did before.

Introduction

The word abandonment originates from Middle French “abandoner,” which can mean either transferring someone out of your purview or “withdrawing support.” The Latin root of the word abandonment comes from *ab* (from) and *bandum* (banner), indicating the deserting of the field in war. Most medical providers are familiar with the legal concept of abandonment, which is defined as a breach of the social contract between a physician and patient to provide longitudinal care. An example of this is when a physician unilaterally withdraws from a patient’s care without first formally transferring that care to another qualified physician who is acceptable to the patient [1]. Other legal examples of abandonment include failure to provide postoperative care, failure to respond to phone calls, or failure to provide cross-coverage.

However, there is a more subtle form of abandonment that does not necessarily have legal connotations but can nonetheless significantly harm patients and strain our relationships with them. Psychological abandonment of this type occurs when patients feel abandoned even when their doctors provide technically good care [2–4]. In his book *The Silent World of Doctor and Patient*, Katz [4] describes psychological abandonment as a feeling of “estrangement” that is as “tormenting as feelings of physical abandonment, perhaps even more tormenting.”

In this paper, we describe scenarios that can lead to feelings of abandonment and discuss strategies to avoid and respond to them. These strategies can help us maintain healing relationships with our patients by maintaining their trust, confidence, and satisfaction. Communicating with our patients in supportive and caring ways requires an interchange and takes time [4–8]. Experienced doctors know this and continue to do so because it is a fundamental component of good care and is rewarding.

What happened in the care of Mrs. B?

Technically speaking, the lymphoma providers were correct when they told her they were no longer responsible for her care. They “packaged” Ms. B meticulously according to evidence-based standards of care and then passed the baton to the bone marrow transplant (BMT) service, which was then responsible for the next step in the algorithm. However, Mrs. B experienced the transfer as a form of desertion. We gain insight into Mrs. B’s feelings by

considering the distinction between *disease* and *illness*, a critical concept framed by Reading [9]. A disease is a structural or physiological abnormality in a patient, whereas illness is the subjective experience of disease, including the patient’s perceptions, distress, and suffering. While disease and illness data may be different classes of information, both are needed to provide comprehensive care. When Mrs. B became ill, she was worried that her transplant, and therefore her life, was in jeopardy. She turned to the people with whom she had a trusted and secure relationship, namely the lymphoma team. Her place on the treatment algorithm meant little to her. Thus, a serious disconnect existed between Mrs. B’s expectations of care for her *illness* and the lymphoma team’s goals for the management of her *disease*.

Dissecting the feeling of abandonment

Gerretsen and Myers [10] articulated a second concept that deepens our understanding of Mrs. B’s feelings when they discussed the role of attachment theory in patient–provider relationships. In this schema, patients derive a sense of security by forming strong, helping relationships with their caregivers. These bonds are often strengthened in life-threatening illnesses, such as cancer, which carry the stigma of death and suffering [11, 12]. These strong relationships create expectations for care in patients that are not necessarily shared or even recognized by their clinicians. In a time of crisis, such as when Mrs. B’s rash and fever alarmed her and caused her to worry about her eligibility for transplant, she was especially moved to seek out her “secure base”, namely people whom she knew and trusted. Patients may also be particularly sensitive to their caregivers’ words during times of crisis when every word can take on an emotionally charged meaning above and beyond normal everyday verbal transactions. As Bedell [13] points out, “being ill inherently humbles and corrodes the sense of self, making patients vulnerable to the words of their physicians”. Thus, while at a cognitive level Mrs. B’s caregiver’s intent may have been to streamline her care, on an empathic level, they missed the message “I am frightened and don’t know where to turn.” The words “you need to consult the BMT team” may have sounded like “you can’t turn here” to Mrs. B.

Circumstances that lead to feelings of abandonment

Severe illness and vulnerability

A patient’s perception of abandonment is proportional to the severity of their crisis and the degree to which we fail to

meet their expectations [13]. Consider, for instance, a healthy patient whose doctor promises to contact her with results of screening blood work following a yearly physical, but forgets to do so. The patient is unlikely to experience intense feelings of abandonment if she calls and learns the results are normal. In contrast, consider a patient with non-small cell lung cancer who is hospitalized for obstructive pneumonia and awaits results of a CT scan to assess response to third-line salvage chemotherapy. Worrying about the results of the CT represents an existential crisis, and such a patient is likely to feel abandoned by her oncologist if he sends the palliative care team to her room to discuss hospice referral without first discussing this major transition face-to-face.

Multidisciplinary care and transition between providers

As healthcare has become more technologically advanced and complex in recent decades, it has also become more fragmented across different subspecialties. Patients often do not know who to call when they have a question or concern, which can leave them feeling abandoned. The patient-centered medical home (PCMH) is a “new” model of healthcare delivery endorsed by a broad coalition of healthcare stake holders that addresses this issue of fragmentation [14]. One key feature of PCMH is care coordination across multiple settings in which patients establish healing relationships with their personal physicians who coordinate and integrate care. While the PCMH model generally refers to primary care, it applies equally well to medical oncology since patients expect to face the uncertainty associated with cancer by partnering with a physician who coordinates the many aspects of their care throughout their illness [2].

The concept of care coordination and integration in large part boils down to accessibility. A worried patient who is unable to speak with his physician or his physician’s designee about a genuine concern is likely to feel abandoned. Accessibility can take many forms, from speaking with a clinic nurse or midlevel during business hours to speaking with the physician by private cell phone. Level of access depends upon the circumstances and unique relationship between each patient and provider. In general, the more trust and rapport we establish with a patient, the greater access we can comfortably provide. The essential requirement is that each patient has the ability to speak to a person who is reasonably qualified to address the concern in a timely fashion. Consider the following strategy:

Doctor: Here is my business card with my office number. I will write my direct cell phone number on the back. However, please only call my cell for truly significant issues. Please do not call me to ask about

logistical issues, such as time of your appointment, fax number, directions, etc. You can call the office staff for that kind of information.

Giving direct cell phone access to patients who seem particularly scared or vulnerable and who are unlikely to abuse the privilege sends the following very powerful messages: (1) “I sincerely care about you”; (2) “I trust you”; (3) “I am here to help you.” Ironically, offering direct access reduces frivolous pages and calls since patients feel secure in the knowledge they can call if they really need to. Thus, the “perception of availability” is a powerful clinical intervention itself [10].

Not fulfilling promises

Mr. A was a 70-year-old man with hormone-independent prostate cancer widely metastatic to bone who returned to the clinic one Friday for a checkup prior to his third cycle of chemotherapy. His chief complaint was new-onset leg weakness, and MRI later that day revealed early cord compression due to vertebral metastases. His doctor admitted Mr. A to the hospitalist service to initiate palliative radiation, which would otherwise not be available over the weekend. In an attempt to reassure Mr. A., his doctor promised to “stop by this weekend to make sure everything goes well.” However, his doctor did not show up since he was not on call and had several family and social obligations that precluded a trip to the hospital. Mr. A looked forward to the visit all weekend, and he felt disappointed and abandoned when his doctor failed to show.

His doctor would have been better off setting realistic expectations by saying “I probably will not have an opportunity to see you this weekend due to other obligations, but you are in good hands. My partner, Dr. B, is on call for our practice this weekend. Please ask the nurses or page operator to page him if you have questions or concerns not addressed by the hospital staff. Dr. B can even contact me if necessary.” This scenario may have disappointed Mr. A, but he would have at least known what to expect. In addition, his doctor would have been able to relax over the weekend without feeling guilty.

Another example of not always saying what we mean is when we promise to call patients with results of tests or multidisciplinary conferences and then forget to do so. Making such promises is reasonable only if we have a reliable system for fulfilling them. A better approach is to say “I plan to call you with your results early next week. However, if you do not hear from me or one of my staff by midday Wednesday, please call us.” This latter scenario establishes realistic expectations and a contingency plan.

Saying “there is nothing more we can do for you”

Transitioning from active treatment to palliative care is particularly challenging for patients with advanced cancer [15]. Most patients hope for cure above all else, or they hope for long life if cure is not realistic. Hope for quality of life is a harder sell for patients who face imminent death. Patients therefore often view transition to palliative care as relinquishing hope, and many also worry about the pain their deaths will cause loved ones.

As difficult as this transition is for patients and their families, it is arguably more difficult for their oncologists [16]. Discussing bad news with patients day in and day out is extraordinarily stressful regardless of how often or how well we do it. Caring for patients with advanced cancer at the end of life also forces us to face our own mortality. In addition, many of us were not formally trained to perform this difficult communication task, which makes it all the more difficult. Heart-to-heart talks with patients about very sensitive topics are also time-consuming. For all these reasons, transition from active treatment to palliative care is often a stressful process that leaves patients feeling abandoned.

Some oncologists use the phrase “I’m sorry, there is nothing more we can do for you” when chemotherapy is no longer an option. Others call in the palliative care team to have the difficult conversation for them, which leaves the palliative care team feeling awkward and vulnerable. Both these approaches leave patients feeling abandoned.

Consider the following strategy for discussing transition to palliative care:

Doctor: “How are you today?”

Patient: “I feel weak, but I am anxious to start my next cycle of chemotherapy.”

Doctor: “Tell me more about how you think your treatment is going.”

Patient: “I suppose it’s going well. You told me last time my tumors were stable.”

Doctor: “What are your goals for treatment?”

Patient: “I want to control the cancer, keep fighting.”

Doctor: “I wish we could resume chemotherapy, but I am concerned you are too weak to take it. Chemotherapy will harm you at this point.”

Patient: “But doctor..., I thought we were going to keep fighting. I can’t give up now, I still have small children.”

Doctor: “We never give up the fight, and we always maintain hope. However you are too weak to take

chemotherapy now. I wish we could restart chemotherapy [17], but I am concerned doing so will be dangerous.”

Patient (tearful): “What are you suggesting doctor?”

Doctor (offering a box of tissues, allowing a few moments of silence): “I think we need to focus entirely on your quality of life rather than treating your cancer.”

Patient (still tearful, but calming down): “What do you mean?”

Doctor: “I mean I do not think chemotherapy will help you at this point. We need to focus on your comfort, and dignity. For instance, we will give you medications for any symptoms you have, such as pain, constipation, nausea, or insomnia. We can also arrange for hospice. Are you familiar with the hospice concept?”

Patient: “Yes, I have heard about it. My mother was in hospice before she died of lung cancer. Doctor, does this mean you will no longer be my doctor?”

Doctor: “If you choose to enter hospice, the hospice doctor will be your primary doctor for day-to-day issues. However, you are always welcome to call me or return to this clinic if you feel well enough to do so. Having said that, most patients choose to receive all or almost all of their care at home after they enter hospice.”

Saying goodbye

The last meeting between a doctor and a patient facing imminent death is particularly uncomfortable and emotional for everyone [18]. How do we provide closure without seeming negative or making our patient feel abandoned? Many physicians avoid “saying goodbye” to patients since doing so may expose feelings of failure at having not saved the patient’s life regardless of how bad the prognosis was at the onset. Hippocrates himself is thought to have avoided goodbyes as a way of shielding himself from blame for his patients’ deaths. However, patients at the end of life need closure for themselves and for people in their inner circle. Patients often regard their physician as part of that inner circle, especially when they have a long-standing relationship. We occupy a special place in their hearts, having cared for them extensively through periods of crisis and vulnerability. Patients are likely to feel abandoned at the end of life if we fail to provide the closure they need [19]. Doing so

can be as simple as saying: “I may not get to see you again. If not, I want to tell you how honored I am to have cared for you. I am inspired by your courage and composure in the face of tremendous challenge, and the love between you and your family”. For the physician, gratitude expressed by some patients at the end of life can help ease the frustration and sadness associated with losing a patient [20] and thereby reduce stress and burnout [19].

Powerful medicine

Let us revisit Mrs. B, the 40-year-old with lymphoma who developed fever and rash while awaiting transplantation. Consider the following alternative approach:

Mrs. B (on the phone with her Lymphoma doctor): “I need to come to clinic today. I developed a rash and fever a week ago.”

Lymphoma doctor: “Tell me more.”

Mrs. B.: “Maybe this is all due to something I ate. I don’t know. It started after I went out to dinner last week.”

Doctor: “What are you most concerned about?”

Mrs. B: “That this could represent something serious”

Doctor: “What do you mean by ‘serious’?”

Mrs. B: “I am worried I will become ineligible for transplant.”

Doctor: “I can understand your concerns. Technically, you are now under the care of the transplant team, so they will need to see you. Nonetheless, I think we can help expedite your evaluation. Let me recommend a course of action. Why don’t you call the transplant service to get an appointment as soon as possible? In the mean time, I will send an email and/or call Dr. D, your transplant doctor, to let him know what is going on. If you still have concerns, please contact me or my clinic staff in a day or two so we can help out. We will make sure you get the care you need.”

Dr. T committed himself to be present and stay with Mrs. B because “nonabandonment” of our patients, particularly seriously ill and vulnerable ones, is a pillar of moral and ethical training and a fundamental attribute of a good physician. As it turned out, Mrs. B got an appointment in the BMT clinic within 24 h and did not need to call the lymphoma service back. More importantly, she felt secure

in the knowledge that her healthcare team truly cared about her, just like she was a member of their family, and that they would never abandon her, no matter what.

Conflict of interest None.

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