



Fostering Sound Medical Treatment Decision Making:

A Focus on Treatment Choices for Breast Cancer



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Abstract

Patients receiving a diagnosis of catastrophic illness are expected to choose among treatment options fairly quickly. Brief therapists can facilitate the process of decision making by assisting patients to overcome common deterrents, including 1.) cognitive overload, 2.) failure to fully comprehend treatment options, 3.) inability or refusal to process information in the presence of a denial defense, 4.) hurried presentation of information by the physician, and 5.) self-imposed time constraints to get decisions made. Many patients later regret the treatment choices they made under those circumstances. From a medical perspective, the best treatments offer a physical cure; however, from a psychological perspective, the best treatments maximize a patient's ability to heal emotionally, socially, intellectually, and spiritually. Therapists in medical settings can make a difference for such

patients by assisting them to systematically consider their options, and can educate clinic staff about ways to minimize framing bias. The involvement of therapists in decision making applies to various diagnoses. However, each diagnosis presents its own unique factors.

Within the context of primary care settings, the focus of brief therapy tends to vary from therapy that occurs within a private practice setting. In a medical clinic, the patient's attention primarily falls within the realm of physical and medical concerns and, quite naturally, so can the initial psychotherapy sessions. In many cases, following their diagnoses, patients have medical treatment decisions to make, but they simultaneously find themselves in the midst of emotional crises that can adversely affect not only themselves, but their friends and families as well.

This is an area in which a supportive and informed therapist can really have a positive impact on his or her patients.

One of the best contributions the therapist can make in primary care settings is to help educate and increase awareness of the ways that physicians and other medical staff can facilitate patient decision making. Once familiar with decision-making theory, one begins to appreciate the complexities involved in deriving decisions from patients that are truly the right ones for them—both in the short and long run.

Because treatment decisions often need to be made fairly quickly, the conditions under which such decisions are made are far from ideal. For example, patients rarely have the medical background to make fully informed decisions; rather, they must choose treatments based on incomplete information and comprehension. Some patients must decide how to weigh the factors of survival and aggressive treatments against the factors of quality of life and less aggressive treatments. For others, there are financial constraints and insurance hassles to consider. During this time, patients find themselves cognitively compromised by high anxiety levels, along with a sense of overload caused by the presence of too many factors and too many options to consider simultaneously (Scott, 1983). Even in the presence of truly compassionate, communicative, and patient physicians, patients often find themselves overwhelmed by the responsibility of choosing among treatment options.

The therapist can guide and assist a patient in his or her treatment decision-making process in a manner that systematically examines the person's philosophy of treatment and then matches that philosophy to the options that are offered. For example, people may find themselves faced with an option that is time consuming, has numerous incapacitating side effects, is expensive, and yet is considered to be "the best treat-

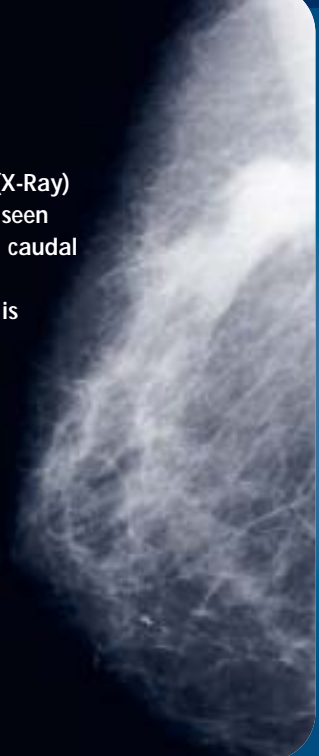
ment" by the physician because it is associated with the best survival advantage. The alternative may be a treatment that can be given at home, has few adverse side effects, and is affordable, yet has no proven curative effects. In this situation, the therapist would want to ensure that the patient feels comfortable enough to identify his or her own philosophy of treatment (e.g., aggressive at all costs, preservation of quality of life at all costs) rather than simply "going along" with the physician's preferences.

The practice of informed consent has established increased trust and enhanced communication among physicians and their patients, along

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Mammography (X-Ray) of breast cancer seen in a right cranial caudal (RCC) view. The cancerous tissue is the large mass.



with several additional benefits. For example, because patients must give their consent for procedures, patients now assume partial responsibility for treatment outcomes. Research shows that treatments are better accepted if the patient and spouse become involved in choosing (Morris & Royle, 1988). Informed consent translates into a reduced chance for lawsuits that might otherwise result from “surprises” associated with procedures. And finally, informed treatment choices translate into better patient compliance (Wynstra, 1994).

One of the drawbacks associated with informed consent is the pure complexity of the thought processes required to conduct a cost-benefit analysis and compare and contrast medical treatment options and their side effects. For the purposes of illustration, in this article we will focus on treatment choices for breast cancer. The treatments of cancer have become much more complex in the past decade as treatment options have expanded from surgery, chemotherapy, and radiation to include hormonal manipulations, biological response modifiers, immune system repressors and enhancers, radioactive isotopes, and so on.

Along with the expansion of treatment options, doctor-patient relations

have become more complex. Patients have generally become more active in making their wishes known regarding treatment decisions, and many are informed consumers, researching the availability of clinical trials listed on the Internet for their particular types of cancer. Treatment options that preserve quality of life have emerged, with many products designed to eradicate disease while minimizing side effects. These are exciting times for the field of oncology, but as treatment complexity increases, the challenges of assisting patients in making informed treatment decisions become increasingly apparent.

The manner in which the information is presented (verbal and non-verbal cues, timing, order of presentation, etc.) is critical in determining which treatment option has an increased probability of acceptance—regardless of the information being presented. The importance of the framing of information will be the primary topic of this next section, followed by suggested ways a clinician could work to minimize such effects, thereby enhancing a patient’s unbiased decision-making process.

Decision-Making Theory

The framing of information has been found to significantly influence decision making regardless of the setting, but in medical settings it can be rather critical. McNeil et al. (1982) presented a hypothetical scenario involving lung cancer to research participants (comprised of both physicians and patients) who were then asked to choose a treatment based on statistical rates of survival. They found that preferences of both physicians and patients between hypothetical therapies for lung cancer varied markedly when their probable outcomes were described in terms of mortality versus survival. Treatment options were rated relatively less attractive when the statistics of treatment outcomes were described in terms of mortality rather than in terms of survival. Surprisingly,

this effect was equally true when the same data was presented to patients as when presented to physicians and graduate students. McNeil et al. concluded that losses tend to loom larger than gains, so the framing of the treatment options greatly influenced the manner in which options were perceived.

Kahneman and Tversky (1984) noted that decisions are sometimes perceived as a choice between retaining the status quo and accepting an alternative. Assuming that the status quo provides the reference level of attributes for a particular choice, the advantages of alternative options will be considered as gains, and disadvantages will be considered losses. Again, because losses are more salient than gains, decisions tend to be biased in favor of going with the status quo. For this reason, the attractiveness of treatment options is contingent on the framing of those options. For example, surgery carries with it a risk of death during treatment, whereas radiation therapy does not. Therefore, surgery is a less attractive option when described in terms of mortality and a more attractive option when described in terms of survival.

Let us examine the choice of surgery for early stage breast cancer (omitting the many complicated medical factors that enter into staging and hormonal status). All other things being equal, the National Institutes of Health (NIH, 1990) concluded that survival rates for early stage breast cancers were statistically the same whether the woman underwent a mastectomy (MST) with no further treatment or chose to undergo a lumpectomy (LMP) followed by localized radiation treatments (LMP-R); therefore, the NIH began recommending breast conservation whenever possible. Given this information, one would wonder what factors enter into women’s decisions to pursue MST rather than the less invasive LMP. Common sense would dictate that convenience and time are considerations, because follow-up radiation is utilized to eradicate any

residual cancer cells in the breast that might remain following the LMP. Fear of recurrence is a consideration for many women who favor removal of the entire breast. In fact, when I first began investigating this topic in 1997, there were still major discrepancies reported across the United States when examining existing pockets of geographical areas in which MST was the prevailing norm despite statistical evidence in favor of breast-sparing techniques (Wynstra, 1994).

But given what we know about decision theory, other factors could be involved; in particular, one might surmise that the presentation of information would have a great deal to do with women's treatment decisions, along with status quo effects, pre-existing bias, and so forth.

People do not make choices based on statistical probability (Kahneman & Tversky, 1984). They are risk-averse when the same choice is framed in terms of an unlikely loss (i.e., 15% chance of surgical complication), and they seek risks when a choice is framed as an improbable gain (i.e., 15% chance of improved survival.) A change of wording from "lives saved" to "lives lost" induces a marked shift of preference from risk-aversion to risk-seeking decisions (Kahneman & Tversky, 1984). The statistical rates of cure quoted by physicians are derived from research population norms; however, for each individual, the information that has meaning is whether the treatment works for him or her. Therefore, the most meaningful approach to assisting a patient in treatment decision making is to narrow down the treatment options based on research results, and then to choose a particular option by matching the patient's philosophy, preferences, and beliefs to the options. In addition, one must note that physicians are human beings, susceptible to the same errors in judgment as everyone else. Despite their training, they are unable to assimilate and then disseminate

the statistics in a manner that is free of personal bias, even when making a specific attempt to do so. The framing of information can occur on a very subtle level; nonverbal cues operate quite effectively. This does not make them inept physicians; this makes them human beings.

Consideration of Patient Values

Many patients place a premium on their physician's opinions. This is sometimes because 1.) patients do not comprehend the medical aspects of the treatments; 2.) patients wish to be regarded as good patients; 3.) patients simply do not know how to make the decisions; or 4.) patients believe this is what they pay physicians to do (i.e., give their expert opinions). These are the patients' prerogatives; however, seldom do patients truly know their physicians well enough to know the physician's philosophy of healing, the physician's values, or the physician's sense of ethics. This is not to say that physicians cannot be trusted; I am inclined to say most of them are wonderfully devoted to assisting their patients in the best way they know how. However, many treatment decisions—especially those that are equivocal options in terms of survival outcome—have vastly different meanings attached to them. Physicians are incapable of determining which treatments are worth the risk for individual patients. They are not trained to evaluate the social implications of, for example, the loss of a breast versus preservation of breast tissue that will result in an imperfect cosmesis given a particular patient at age 45 versus one who is 58. These are not questions that can be evaluated or answered by one's physician. Yet countless patients rely on their doctors for this advice, and many later regret it. In a study by Margolis et al. (1989), more than half of all mastectomy patients later regretted not having obtained a LMP with radiation treatments. Following the surgery,

many of them had unexpected problems related to body image, emotional reactions, avoidance of sexual relations, and a decline in social and leisure activities during their recoveries (Maguire, 1975).

Deterrents to Sound Treatment Decision Making

Haste

Therapists should encourage patients to move slowly. Siminoff et al. (1989) found that 82% of those surveyed had made their treatment decisions during their very first visit to receive their diagnosis (while still in the office). Thus, many decisions are made hastily, and many are later regretted. The oncologists or surgeons often attempt to move fairly quickly in response to an aggressive disease, but statistics indicate that the time period from the emergence of the first aberrant cell to the point of diagnosis averages 8 years (NIH, 1990). Therefore, a delay of a few days to make a sound decision is an option that is warranted for most patients.

Regional Preferences

Statistically, there is a geographic variance in the rate of breast preservation associated with comprehensive cancer



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centers in comparison with rates found in teaching and community hospitals (Hanks, 1991). Higher rates of conservation also exist in states in which informed consent statutes are in place (Wynstra, 1994). One can speculate that some of the discrepancy is related to ease of access to a nearby radiation facility; one might also speculate that this is partially related to surgeon bias or inability to present treatment options impartially. Finally, regional differences may be a reflection of geographically predominant cultural beliefs related to a physician's role as decision-maker versus collaborator. Rates have been found to vary based on whether the patient was initially seen by a radiation oncologist or a surgeon, respectively (Wolberg, 1987).

Pre-Formulated Contingencies

Nothing can prepare a person for being diagnosed with a catastrophic illness, yet people commonly think, “What would I do?” when they encounter friends or family with a similar problem. Therefore, most people have a sense of where they stand in terms of treatment boundaries. Some people state, “I don't want to live if I have to be a vegetable,” and others declare, “I want to use everything medicine has to offer if I become ill.” Yet when they find themselves in the actual situation,

their reactions are unfamiliar to them. People do not respond to catastrophic threats in a predictable manner (Rowland, 1989). They may delegate, delay, or defer their decisions, or they may fail to deliberate at all, making snap decisions before the results of the laboratory tests have even been returned; regardless of their reaction, it tends to be atypical in comparison with decisions that are made for routine procedures.

Other Factors

Many patients have fears about the possible long-term effects of radiation therapy, and therefore seek to avoid any treatment option that includes radiation. Unfortunately, little is known about the long-term risks and few discussions include this consideration. Another area given little “air time” is information about reconstruction. Women may be told this can be an option, but seldom do they visit with a plastic surgeon prior to their initial treatment surgeries, and frank discussions of likely cosmetic outcomes and sexual ramifications are often omitted or minimized in favor of discussion about survival. Transportation is another consideration for treatment choices since LMP is routinely followed with 6 to 7 weeks of daily radiation therapy.

Denial

A reaction to illness that is characterized by denial may involve only suppression of the information about treatment options, or it may extend to avoidance and denial of the diagnosis and disease itself (Rowland, 1989). Both have great potential to interfere with treatment, but as long as a patient is willing to receive and comply with treatments, it is not recommended that the brief therapist take it upon him or herself to begin breaking through the denial. Denial may actually afford patients some protection from the full force of information they are not prepared to handle emotionally. Given time and gentle care, almost every

patient will move toward greater clarity about his or her situation, especially once treatment is initiated. The wise therapist will look for signs of this and will also ask the patient to help him or her understand the diagnosis (under the guise of being helpful to the therapist). This is a convenient way to assess their understanding and also provide an opening to further clarify and foster a better emotional adjustment to the illness. Because denial can be somewhat protective, it is not recommended that patients in a state of fragile denial about their disease join a support group, as groups are notorious for their tendency to break through denial rather bluntly.

How to Intervene from a Brief Approach

Assessment

In a retrospective pilot study (Donaghy, 1998), patients identified five major areas for consideration in evaluating types of surgery for breast cancer. These included cosmesis, the physician's opinion, short- and long-term effects, and level of understanding (i.e., feeling informed enough to make a decision). It is notable that cosmesis was the most robust factor to emerge from the factor analysis. Perhaps this is not so surprising given that the surgical choices for early stage breast cancer are statistically equal in terms of survival outcome (Ray et al., 1986).

The therapist can employ the Breast Cancer Treatment Decisions Inventory (BCTI; see Appendix) if desired, or can merely use the content as a guide for assisting women in considering the options from perspectives they may not have considered. Examining the responses can lead to clues regarding the patient's underlying perspective on treatments. Alternatively, a guided imagery exercise can be conducted in which the patient visualizes and viscerally experiences each alternative and its probable outcomes in terms of advantages, immediate and long-term side

effects, best and worst possible scenarios, and so forth.

Promote Family Communication

Family members often have differing opinions about treatment, and often come to terms with the diagnosis on a different timetable than the patient does. This means that their support may not be available when needed, or it may fall short of expectations, and at times, the family's maladjustment can deter the patient's progress in adjusting to illness. The therapist may assist in facilitating adjustment and supporting the patient in the presence of the family in such cases. Also, family members may hesitate to express their anxiety or fears, feeling they must always present a positive outlook around the patient. Patients often reciprocate by hiding their fears. The therapist should be alert for this common occurrence, as it is easy to resolve through open communication with the patient and family present, or even privately with each individual. This approach quickly facilitates family support and ameliorates the patient's sense of isolation.

Sometimes patients need assistance and encouragement in soliciting social support. The diagnosis and subsequent logistics of doctors' visits, lab tests, and prescriptions can make patients feel they are a burden. Metaphors and anecdotes can be used to explain the importance of patients using the support available to them. One that is particularly effective relates the story of a small child who sees her mother crying and who quickly rushes to write a "get well" card. Rather than pushing her daughter away, the mother embraces her and tells her how wonderfully loved she feels. The daughter then grows up to be a loving person who feels she has value. The story can also be told from the opposite perspective, depending on the patient's level of resistance to asking for help. The use of a metaphor like this can effectively reframe the solicitation of help into that of a "gift" in which

the other person feels useful and needed.

Analyze the Cost-Benefit Ratio

During the decision-making phase, the therapist should assess the patient's value system concerning where she falls along the passive/aggressive treatment continuum. The therapist can help her analyze the cost-benefit ratio and come to a realization of how aggressive she wants to be toward the disease, and at what cost. By asking the right questions, a woman who does not fully understand the treatment options can still have her opinion honored; by sharing her philosophy with the oncologist and surgeon, the patient can be assisted in choosing an option that most closely matches her belief system.

Visual Decision-Making Models

Whelen et al. (1999) devised an excellent visual decision-making aid called a "decision board" for guiding patients through a cost-benefit analysis of breast cancer surgical options. His model can be very useful in helping patients make decisions without the use of numbers, but instead with a visual representation of their choices and accompanying side effects. Because people can more efficiently process information from multiple modalities (visual and auditory versus just an auditory explanation) (Bandura, 1969), this has been shown to be an effective tool in enhancing patients' abilities to process information.

Assess Emotional Reactions

Although each person is unique, the literature generally recognizes common categories of stress reactions that may occur in patients diagnosed with catastrophic illnesses. These include the "5 Ds": distance (emotional and relational isolation), dependency (on friends, family, and physicians), disability, disfigurement, and death (Rowland, 1989). The first 10 days following diagnosis may be fraught with a sense of existential angst marked by fears and preoccupation

with life and death issues (Weisman & Worden, 1976). For most patients a sense of depersonalization, marked by inefficiency in the processing of information, usually begins to return to baseline within a period of two weeks following diagnosis (Holland, 1989).

Perhaps the single most therapeutic intervention the brief therapist can use is to listen by inviting the patient to "start at the beginning and tell me everything that has happened up to this point," and then sit back and get absorbed in his or her story. This leads the patient to feel understood and heard, and identifies you as an ally. Most of the professionals patients see are specialists who only get a snapshot view of them from the perspective of their specialties, rather than as a whole person. It is important for patients to be able to view themselves from the whole-person perspective when choosing their treatments. Patients may also be encouraged to formulate their opinions about their treatments as a result of being encouraged to verbalize them aloud.

Treating Pre-Morbid Conditions

For patients with pre-existing psychological difficulties, symptoms may be exacerbated in the presence of medical challenges. Such patients' emotional reactions can quickly be stabilized through the short-term use of anxiolytics and hypnotics if desired. Or, preferably, patients can be led through hypnosis to guide their decisions and adopt improved coping skills. A wonderful approach is to guide them to contact their own inner physician, asking for wise council regarding the medical choices that will best match their needs for healing. This can be introduced by simply asking patients to close their eyes and move their attention inward. Whether they enter into a deep trance or not, you will find they are able to better focus their attention, rally inner resources, and establish a sense of self-responsibility and empowerment—

often the first two traits to fail upon receiving a medical diagnosis. This is a valuable skill for patients to learn and can later be utilized in the management of pain, nausea, fatigue, lassitude, and other common disease and treatment-related side effects.

Concluding the Initial Phase of Therapy

For the majority of patients moving through the initial phases of reaction to diagnosis and treatment decision-making, a minimum of 1 to 2 clinical sessions would be required. However, it is recommended (because the person is just beginning an unknown course of illness and is likely experiencing a sense of depersonalization and anxiety) that a follow-up visit be scheduled to occur just prior to the initiation of any adjuvant treatments that are planned. This will be the time to begin a discussion of preventive services you may offer, such as teaching them self-hypnosis, medication management, or assertiveness skills, or simply to reassess their emotional reactions to illness. You may also wish to assist them in locating support groups that would assist them in combating a sense of isolation, answer their questions, and help normalize their situation.

The therapist can help inoculate patients against likely periods of upcoming difficulty by normalizing them and helping them know the difference between a time-limited reaction of brief duration versus one for which they may wish to contact you again. The expected periods of increased anxiety occur during the initial diagnostic procedure, during the treatment decision making, during the initial treatment, once treatments are completed and the patient is no longer actively combating the presence of cancer, during annual follow-up visits, and during the anniversaries of the diagnosis. Each juncture carries with it a feeling of increased vulnerability, each is a reminder of mortality, and each serves

as a reminder of the loss of a sense of "normalcy" they once enjoyed.

Greasing the Wheels

Once the decision-making phase is accomplished, it is important to maintain close contact with the patient's physicians by placing a progress note in the medical chart, and through informal "curbside" updates that take place in contacts within the clinic. These assist your patient to have his or her preferences heard, improve doctor-patient communication, educate physicians about how to utilize your services, inform physicians of any ongoing issues you plan to address, and inform physicians of your overall impression of the patient's psychological health. Such communications also serve to augment physicians' assessments and reinforce your relationship with a source of potential future referrals. Usually, once you have assisted a physician by smoothing out a difficult situation (addressing a patient's anxiety, depression, loss of hope, fear, indecision, non-compliance with treatment, etc.) or reiterated an educational point for a patient that was not understood via the doctor, that physician will begin to find that he or she has many other patients who could benefit from your services as well.

Summary

Patients receiving a diagnosis of catastrophic illness become cognitively overloaded, often fail to fully comprehend their treatment options, may engage in an inability or refusal to process information in the presence of a denial defense, often receive a hurried presentation of information by the physician, may face self-imposed time constraints in their drive to get decisions made, and may later regret the treatment choices they make under these circumstances. From the medical perspective, the best treatment offers a physical cure; however, from a psychological perspective, the best treatments

maximize a patient's ability to heal emotionally, socially, intellectually, and spiritually. Therapists in medical settings can make a difference for such patients by assisting them to systematically consider their options, and can educate clinic staff about ways to minimize framing bias. If half of all patients receiving MSTs later regret their choice, then further support in decision making is clearly needed.

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Appendix

Adapted from the Breast Cancer Treatment Decisions Inventory (Donaghy, 1997).

CONCERNS ABOUT COSMESIS

1. I will choose my surgical treatment based partly on how it might affect my feelings of attractiveness afterward.
2. In choosing my surgery, an important consideration is that my breasts remain symmetrical (similar in size and shape).
3. My feelings of sexual attractiveness affect my choice for surgical treatment.
4. My choice for surgery is affected by the predicted appearance of my breasts after surgery.
5. I am worried about how my breasts will look after surgery.
6. My choice between a lumpectomy and

mastectomy is affected by the availability of breast reconstruction.

7. My choice of surgery is based on how I think I will react emotionally to the effects of the surgery.

CONCERNS ABOUT BEING INFORMED

8. Once my surgical treatment plan is chosen, I will feel confident in the decision.
9. I have been given adequate time to decide what type of surgical treatment to pursue.
10. I feel able to make a choice on the type of surgical treatment very quickly.
11. I am able to think very clearly about my treatment decision.
12. My physician informed me adequately about my surgical treatment options.
13. I have received adequate educational materials from my physician on surgery options prior to making the decision for treatment.

CONCERNS ABOUT THE PHYSICIAN'S ROLE

14. I consider it my doctor's job to choose the surgery that is best for me.
15. I prefer for my doctor to choose the surgical treatment for me
16. I would like my doctor to choose my surgical treatment while taking my preferences into consideration.
17. I do not wish to participate in the decision about my surgical treatment for breast cancer.
18. I prefer to choose which type of surgery to receive, using others only as consultants.

CONCERNS ABOUT SHORT-TERM EFFECTS

19. I will choose the surgical treatment that interferes the least with my work schedule.
20. I will choose the surgical treatment that interferes the least with the quality of my life.
21. I will choose the surgical treatment that interferes the least with my non-work-related activities.
22. I will choose my surgical treatment based on the amount of time required for treatment and recovery.

23. I will choose my treatment based on what is best for me in the short-term.

24. I will choose the surgical procedure that will minimize my recovery time.

CONCERNS ABOUT LONG-TERM EFFECTS

25. I feel it will improve my odds for survival to choose a mastectomy over a lumpectomy.
26. I want my breast removed so I do not have to worry that my cancer might come back.
27. My fears about radiation therapy affect my surgical treatment choice.
28. My fears about the longer-term effects of radiation therapy affect my choice for surgery.

About the Author

Kathleen Donaghy, Ph.D., HSPP, is a licensed counseling psychologist with a specialty in behavioral medicine. Since 1996 she has developed advanced clinical experience in oncology and cancer symptom management. Prior to relocating to Phoenix, she served as Regional Director of Oncology Symptom Control & Research with Community Cancer Care, Inc. in Indianapolis, Ind. (a network of over 30 hospitals across the state of Indiana.) She has over a dozen psycho-oncology publications in professional medical journals, has presented her findings in a number of national conferences, and is a frequent speaker for cancer support groups and physicians' oncology rounds. Additionally, she has provided consultation-liaison services in over a dozen hospitals and served as an adjunct professor in the Department of Counseling Psychology at Ball State University in Indianapolis. She serves as a reviewer for the *Journal of Palliative Care* and is a clinician with Doctors of the World. Dr. Donaghy currently has a private practice in Phoenix.

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