

Run for Your Life: The Reaction of Some Professionals to a Person With Cancer

By Marianne Amir and Gregory P. Kalemkerian

ACCORDING TO all major psychological and philosophical theories, death anxiety is the most basic of all anxieties.¹ Some of these theories even propose that all other anxieties are, in effect, derivatives of death anxiety. By nature, human beings will expend substantial effort to avoid confronting the most painful and devastating emotion of all, the feeling that life is coming to an end.¹ Some people are fortunate in that they live the greater part of their lives without ever having to confront death directly, thereby avoiding death anxiety. Many others are not as lucky, and are forced to face the prospect of dying on one or more occasions. One such circumstance is the diagnosis of a malignant disease with a high probability of causing death in the not-too-distant future. Although some people rapidly develop a full and acute awareness of their life-threatening situation, others do not, either because of the withholding of accurate information by caregivers or a lack of personal insight. In either case, as the illness progresses, death anxiety will inevitably arise.

Human beings are blessed with various defense mechanisms that allow them to avoid the intense emotional pain caused by death anxiety.² Although both healthy and sick people readily use these defense mechanisms, healthy people can securely deny and repress their anxiety because they are not confronted with an actual threat. Sick people do not have this luxury. When sick people voice these anxieties and fears, they are often met with resistance, or even hostility, from those who are healthy. This article describes the various strategies used by healthy people, often subconsciously, to avoid confronting their own death anxiety, and offers recommendations about ways in which those who interact with sick people can understand and eventually overcome their natural defenses.

DR AMIR'S PERSONAL EXPERIENCES

I received my first diagnosis of cancer 22 years ago at the age of 30 when I was the mother of two small children and was found

to have malignant melanoma with axillary lymph node involvement. I soon learned that this was a virulent form of cancer with a poor prognosis. Luckily, against the statistical odds, this disease has never recurred. In the ensuing years, I raised a family, became a clinical psychologist, obtained my PhD, and became a tenured faculty member at a major research university. Three years ago, during a sabbatical in the United States, I was diagnosed with breast cancer. Despite extensive treatment, the disease recurred within a year. Since this latest diagnosis of cancer, I have undergone five operations and have been treated almost continuously with intensive chemotherapy or radiation. Thus, most of my adult life, but particularly during the last 3 years, I have been living in the shadow of advanced cancer and its ultimate implications. Despite the fact that I function normally (at least according to socially acceptable norms), I do not forget the context of my life for one moment.

The World Health Organization defines "health" as a state of physical, mental, and social well-being, not merely the absence of disease or infirmity. The pathogenic paradigm, which is embraced throughout the Western world, classifies people in a dichotomous manner as either "healthy" or "diseased." In contrast, Antonovsky³ suggests that every person lives on a continuum between "ease" to "dis-ease," beyond the mere presence or absence of physical illness. The fact that I am currently in remission does not mean that I feel good or that I am at "ease." I feel "dis-eased" and spend much time worrying about my fate. When I undergo computed tomography scans or laboratory tests, I become extremely anxious because the results of such tests have direct implications on my life expectancy. However, I have found that when I express my fears, some healthcare professionals and friends will almost reflexively criticize me for being anxious, for not feeling well, or for having negative thoughts. The "professional" in the title of this article refers to both healthcare professionals with whom I have interacted throughout my treatments, and some friends and family members, who are almost exclusively professionals: scientists, physicians, dentists, teachers, engineers, business people, and so on. I emphasize this point only to refute the possible claim that they are acting out of profound ignorance or a lack of enlightenment. Ironically, during the last 10 years, my academic research has focused on quality of life in disease and health, and I now find myself in the uncomfortable position of being both researcher and researchee.

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Submitted January 17, 2003; accepted July 18, 2003.

Authors' disclosures of potential conflicts of interest are found at the end of this article.

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0732-183X/03/2119-3696/\$20.00

PSYCHOLOGICAL COPING STYLES

The responses to her expressions of emotion that Dr Amir has noted can be explained, at least in part, by the desire of healthy people to avoid confronting their own death anxiety. According to Plutchik's theory of emotion,⁴ basic human emotions evoke ego defenses and coping styles. Ego-defense mechanisms operate on a subconscious level to resolve or conceal conflicted emotions and anxieties, whereas coping styles are cognitive responses that allow an individual to adapt to conflicted emotions and stresses. Unlike ego-defense mechanisms, particular coping styles do not imply specific psychopathology. Coping styles are the ways in which individuals can deliberately behave to avoid anxiety and frustration. In accordance with Plutchik's theory, specific conflicted emotions can trigger specific coping styles: fear leads to suppression (the purposeful avoidance of a problem or situation); sadness leads to replacement (finding alternative solutions to a problem); disgust leads to blame (shifting responsibility for a problem onto other people or external factors); anger leads to substitution (engaging in alternative, tension-reducing activities); and the inability to accept reality leads to minimization (down-playing the importance of a problem or situation).

The strategies some people use when faced with the stress of interacting with a diseased individual can be understood within the framework of Plutchik's theory, and can be divided into two major categories: those that impose physical distance, primarily through avoidance of the diseased person, and those that impose psychological distance by delegitimizing the emotions expressed by the diseased person.

PHYSICAL DISTANCING STRATEGIES

Some of Dr Amir's friends, but mostly acquaintances and a few physicians, have employed physical distancing strategies that are all variations on the coping style of fear-based suppression, in which people purposefully shun direct interaction with a patient to avoid confronting their own fears and death anxiety. These strategies can be categorized as follows.

Avoidance

Physical avoidance is the most basic way to create distance. Some acquaintances and friends may disappear entirely from the diseased person's life. In the medical context, Dr Amir encountered this tactic from two physicians. First, from a surgeon who needed to be prodded to communicate with her after a procedure and then was unduly abrupt and evasive when presenting unfavorable results, and later, from a physician who kindly wrote to a colleague for advice, but then left the colleague's grim response with a secretary for Dr Amir to pick up and read on her own without professional or emotional support. Perhaps the latter physician had the mistaken view that because Dr Amir is a mental health professional, she could more easily deal with the implications of her life-threatening illness.

"I Did Not Want to Disturb You"

Some friends will call or visit infrequently, and when they do, they always begin by explaining that they have not been in touch

because they "did not want to disturb you." In reality, did they not want to disturb the diseased person, or themselves?

"It Is So Difficult to Speak to You"

Some friends will not call or visit for long periods of time because they find it difficult to converse with the diseased person. Others will relate their own prior experiences with the illness or death of someone else close to them, and then explain that it is too difficult for them to cope with another round of sickness or loss. Ironically, the diseased person will frequently feel the need to apologize for causing them such discomfort and will end up providing emotional support to the caller.

"No Need to Call Back"

Some people will telephone at times that they know the diseased person is unlikely to be home and leave a message such as, "I just wanted to tell you that we are thinking about you, but there is no need for you to call back." Another variation on this theme is to send flowers or a gift with a note stating that there is no need to call the sender to offer thanks.

PSYCHOLOGICAL DISTANCING STRATEGIES

Psychological distancing strategies are more sophisticated than physical distancing strategies. People may call or visit and display friendly, supportive behaviors as long as the patient refrains from bringing up topics that are deemed to be distressing. If this occurs, they will use a variety of tactics to suppress their own fears and anxieties.

Ignorance Is Bliss

If you pretend it is not there, it will go away. A fairly common strategy employed by friends and acquaintances is to refrain from asking the patient how he or she is, though they may enthusiastically inquire about the well-being of another family member who has had a relatively minor illness. If asked, these people frequently explain that they do not want to remind the patient about the disease, as if the patient could forget for a single minute that he or she has a life-threatening illness. It is more likely that, by not asking, the person is avoiding the need to confront the patient's grave situation. Others will take a more direct approach by immediately saying, "you'll be fine," and then moving on to other less threatening topics of conversation. In effect, they are avoiding being burdened with the patient's distress. This strategy fits the coping style of suppression.

Delegitimizing Distress

When a patient expresses sadness or other negative emotions, some people will immediately respond in a manner that suggests that the patient's feelings are not legitimate or acceptable. For instance, in reaction to a patient's expression of fear, a person may respond, "Why think that way? Why not think about something positive?" or "Why do you focus on the worst?" When Dr. Amir first received the diagnosis of breast cancer, she naturally cried. A social worker who was present responded by saying, "Some people bring the disease on themselves by being depressed," indicating that the patient's emotions were illegiti-

mate. Similarly, a clinic nurse advised Dr Amir that, "The most important thing is not to panic and bother the doctor with all kinds of problems." In other words, it is not acceptable to be afraid when you believe that death is approaching. These behaviors exemplify the coping style of minimization or the avoidance of a difficult situation by diminishing its importance or consequences.

"Get Out and Do Something!"

The amount of trivial advice that people offer patients with cancer could fill an encyclopedia. Some of this advice is medical, but much of it could be summed up as, "How not to be unhappy." A common reaction to a patient's expression of unhappiness is a trite suggestion, such as, "think positive," "be optimistic," "go see a movie," "drink camel milk," "eat green vegetables," "meditate," "do shiatsu," and so on. The implication is that the patient's distress (and, by implication, the disease) is something that can be controlled or eradicated through mental exercises. Some of this stems from frivolous popular publications that often suggest that cures can be delivered through the power of positive thinking, with the misbegotten implication that those who succumb are to blame for their own demise. Many people embrace this simplistic concept because it allows them to believe that if the disease can be controlled in this manner, then they themselves can avoid it. It is difficult for many people to accept that there are situations that either cannot be controlled or do not call for control. This response represents the coping styles of sadness-based replacement or anger-based substitution, in which the individual indulges in alternative activities to reduce distress.

"Something Is Wrong With You"

Some people will protect themselves by blaming the patient. They want to believe that they, in the same situation, would act differently, perhaps more constructively, thereby protecting themselves from inevitable death. Among Dr Amir's experiences with these types of reactions to her grief were a physician who described her as being "hysterical" when she was diagnosed with metastatic disease, a relative who wrote a long empathic letter that ended with "I feel so bad, especially when I know how you take these things," and a friend who responded to Dr Amir's expression of discouragement with, "What is discouraging, your attitude or your disease?" These reactions reflect the coping style of blame, in which individuals protect themselves from the disgust of death or disease by holding the patient responsible for his or her own situation.

"You Should Know Better, You're a Professional"

Because Dr Amir is a mental health professional, some people expect her to be able to cope with her disease and impending death without external support. When she expresses worry, they respond with inane comments such as, "It's interesting how the cobbler walks barefoot." They clearly do not understand the obvious fact that psychologists, doctors, and other health care professionals share humanity's anxiety and fear when facing death. Although oncologists may become inured to the constant

presence of death in their professional lives, facing their own death or that of a loved one is an entirely different experience. These reactions, a variation of the coping style of suppression, allow the individual to avoid dealing with the patient's distress by supposing that the patient can deal with it himself or herself.

DISCUSSION

The world prefers happy people that do not suffer or die and, thus, do not force others to face their own death anxiety and inevitable mortality. It is likely that the primary motivations behind the distancing behaviors described in this article are that most people have difficulty coping with their own mortality and that intimate emotional interactions with diseased individuals can disturb their fragile defenses. Alternatively, these avoidance behaviors may be a premourning strategy that is based on the rationale that if they distance themselves now, it will be easier to cope at the time of the patient's death. Regardless of the motivation, these behaviors can be extremely painful to patients, creating situations in which they not only must face the reality of having a terminal disease, but also must accept the possibility that they must do it alone.

All of the well-meaning comments from friends and acquaintances usually do not make patients feel less sad or afraid, but rather, they can create a feeling of profound isolation, leaving patients alone with both their disease and their fears. Patients may also feel as though they have failed an important test. If they would just smile and say, "I am fine," as if they love having cancer, then everyone would applaud them as a tower of strength and resilience. This situation is reminiscent of the Old Testament story of Job, who endured endless tragedies and suffering only to be chastised by his friends for his failings. He found himself distanced from God and his friends, an isolation that ultimately intensified his distress.

Dr Amir is fortunate enough to have a large supportive circle of understanding friends, whose so-called foul-weather friendship includes seeing each other through difficult times. In addition, she has a sympathetic oncologist, whose first words when the cancer returned were, "Remember you are not alone in this." He allows his patients to shed a tear if they wish, never telling them that they should or should not feel a certain way. He accepts their anxiety and fear, without judgment, and is always available to comfort them when these feelings become overwhelming. Dr Amir has also found strong support from her colleagues and students, both those that she sees on a daily basis and those in her larger classes, who otherwise can seem remote. Perhaps these young students are less aware of their own mortality, and thus are not so intimidated by proximity to such a dread disease.

Of course, Dr Amir's interpretations of the behaviors exhibited toward her during her illness are subjective, and other patients might react to them in different ways. Nevertheless, health care professionals need to be aware that their behaviors can amplify the feeling of isolation that is so common among those with terminal illnesses. To care openly for cancer patients, oncologists must first acknowledge their own fears and recognize the difficulties inherent in the prospect of facing one's own

death. This insight in itself is probably the most useful tool that health professionals can bring into their relationships with the terminally ill. Most patients will greatly appreciate knowing that their physician understands that the situation is distressing, and that the physician will help in any way possible to control both the patient's physical and psychological suffering. Oncologists also need to make it clear that the care they provide will not be confined to the treatment of the disease, but will encompass all of the patient's problems and concerns. Such an approach will also help to overcome the real anxiety that most patients have about being abandoned once anticancer therapy is no longer indicated. Frequently, the best strategy for coping with the emotions of cancer patients is to just be there, silent and supportive.⁵ Brief words of understanding, such as, "Is there anything I can do?" or just a simple physical touch can lessen the sense of isolation and be deeply comforting. All health care workers who come into contact with patients with cancer and other serious diseases need to understand that listening to patients' expressions of emotions is an important skill that must

be consciously developed. It is far too easy and common for oncologists to dismiss their patients' emotions, either directly or indirectly, and to focus instead on the medical plan of action and the next step in therapy. The aim of the health care team should be to create a secure environment of unconditional trust that patients can rely on to mediate between their inner world and the outside reality—an environment similar to that of maternal holding.⁶ As for the many other people with whom cancer patients come into contact, we entertain no delusions that their basic avoidance reactions can be changed. These behaviors are based on the most fundamental aspects of human nature. We all fear death, but the cancer patient has unwillingly become the earthly representative of the Angel of Death. It is no wonder that some people run for their lives. It is amazing that not all of them do.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The authors indicated no potential conflicts of interest.

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