

When the Physician-Researcher Gets Cancer

Understanding Cancer, Its Treatment, and Quality of Life from the Patient's Perspective

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The authors, both medical researchers, describe their personal experiences with cancer, its treatment, and its effects on their lives. They discuss the “eight Ds” that represent their concerns as they navigated this permanent disruption in their lives: diagnosis, dying, discomfort, disability, drug and other treatment effects, dependency, doubt, and death.

Let me suggest that the bad things that happen to us do not happen for any good reason which would cause us to accept them willingly. But we can give them a meaning. The question we should be asking is not “Why did this happen to me?” That is really an unanswerable, pointless question. A better question would be, “Now that this has happened to me, what am I going to do about it?”

Rabbi Harold S. Kushner¹

This article describes two journeys through cancer's innermost circles of Hell, taken by two physician health services researchers, one senior and one more junior. It is *not* a comprehensive review of life with cancer. Rather, this article describes our personal experiences as we traveled this challenging, often frightening, and sometimes rewarding road. We offer our insights and challenges to the cancer research community to help them better focus their research on outcomes that matter to patients: not just length of survival, but also the

They also discuss the beneficial effects that cancer has had on their lives and end with suggestions for clinicians and outcomes researchers who seek to assess and improve quality of life among persons with cancer.

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quality of life, quality of death, and making the most of life during the dying process.

Case 1

WMT was a 48-year-old academic general internist, chief of an academic division of general internal medicine and geriatrics, with a 20-year history of performing health services research with a focus on improving health-related quality of life. His medical history included having three remote minor episodes of upper-gastrointestinal bleeding, chronic cluster headaches, reconstruction of a torn anterior cruciate ligament, and in the previous year, Mohs surgery for the removal of a basal cell carcinoma on his forehead. Important personal history included his being, for a short time, the primary caregiver for his father-in-law before he died of lung cancer a year before WMT's diagnosis.

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Beginning in November of 1999, he began to experience recurrent bouts of left anterior pleuritic chest pains, myalgias, midthoracic back pain, and dysphagia. In late February of 2000, his primary care physician discovered a firm, 2×3 -cm right supraclavicular mass. Fine-needle aspiration yielded cells consistent with large cell non-Hodgkin lymphoma. Abdominal and chest computed tomography scans showed mediastinal adenopathy, with a large mass compressing the midesophagus, periaortic adenopathy, and a 3×3 -cm mass in his spleen. With the diagnosis of stage IIIA non-Hodgkin lymphoma, he underwent six courses of standard chemotherapy with cytoxan, adriamycin, vincristine, and prednisone. Complications of chemotherapy included an autonomic neuropathy (transient gastroparesis and persistent constipation) and a peripheral neuropathy (persistent numbness of his distal feet and fingertips, loss of muscle stretch reflexes, and moderate ataxia resulting in a number of falls). Rapidly progressive generalized myopathy developed after his fourth course of chemotherapy, despite a rigorous routine of running and weight lifting, and resulted in diffuse muscle atrophy and proximal weakness causing moderately severe difficulties in standing, walking, and climbing stairs. Despite these complications, he missed less than 2 weeks of work. The myopathy and neuropathy had partially resolved but still limited his activities 1 year after the last round of chemotherapy.

Case 2

EDM was 36-year-old internist who had just finished a 4-year fellowship in epidemiology and cancer prevention in North Carolina, and was returning to Cleveland with her family to begin her first job as an academic internist and health services researcher. She had begun to delve into the questions of racial disparities in end-of-life decision making for cancer patients, and had helped to establish a mammography registry in North Carolina. She hoped to use her new skills and knowledge to begin exploring disparities in cancer care in Cleveland. Her medical history consisted of a broken collar bone at age 13 and several episodes of acute sinusitis.

In November of 1996, 3 months after starting her new job, she noticed a breast lump and in very rapid order had a diagnosis of stage II breast cancer with micrometastases to three of six lymph

nodes. She had a lumpectomy, entered a clinical trial of accelerated doses of adriamycin and cytoxan, and finished her primary treatment with 6 weeks of radiation therapy to her left breast. She lost her hair over the 8 months of therapy, and although she wore scarves with her kids and her patients, she could not escape the fact that she looked like a cancer patient. She threw up occasionally, slept more, and finally had to stop working because of exhaustion. On her 3-month follow-up mammogram, she was diagnosed with extensive ductal carcinoma in situ of the other breast. After some discussion, she chose to have a bilateral mastectomy with immediate implant reconstruction. After many months of intensive exercise (including ice hockey) and stretching, she still had a somewhat limited range of motion of her left arm and mild lymphedema requiring lymphatic massage and wrapping. Finally, in November of 2000, she found a new mole on her right calf that was diagnosed as melanoma in situ. With her history of bilateral breast involvement and melanoma, she opted for genetic testing for *BRCA1/BRCA2* mutations. Luckily, there was no evidence that she had either of these mutations.

The Eight Ds

Below we delineate eight general concerns (the "eight Ds"), more or less in chronologic order, that we suffered during our battles with life-threatening cancer. Each depicts a stage of evolution in our responses to these malignancies and their management.

Diagnosis

With the diagnosis of cancer came the sudden realization that our lives would never again be the same. We would never again look at life the same way, and others would never again look at *us* in the same way. Our options and choices in all aspects of our lives were suddenly different, and have continued to be different. There was an undeniable shock to our lives that disrupted all of the carefully constructed systems and routines with which we moved from day to day. We were faced with the sudden realization that *we have cancer*, and this realization continues to be reflected in all aspects of our lives. An example was found in the mindless greetings that we received

from friends and colleagues after our cancer had been diagnosed. How does someone with the recent diagnosis of cancer answer the question, "Hi! How are you?" The most accurate answer is "Not so good. I have cancer." But this inevitably led to a lengthy discussion that, especially early in the course of cancer, we tended to avoid. Also, the "How are you?" question often comes from casual acquaintances; we often did not want to discuss our illness with such persons. Hence, for us at least, the most frequent response to "How are you?" was "OK. How are you?"

The shock of the cancer diagnosis was painful and introduced chaos into our daily routines, routines that we had carefully crafted to maximize efficiency in performing everyday tasks. The overall feeling was one of loss and uncertainty. How should we rearrange our incredibly busy lives to continue to move forward, even if at reduced speed? What should our priorities be? What, if anything, should we eliminate? Eliminating an important activity felt tantamount to giving up and was difficult to do, especially early in our course of the disease. So we tried to carry on despite (and at times denying) our disease.

Limitations of function related to our initial treatments also interrupted our daily routines, making it difficult to make everyday decisions. The response to changes in our routines and the resulting chaos spilled over into our personal lives, affecting the inevitable reconfiguration of relationships with loved ones and friends that followed the diagnosis of cancer.

Dying

As practicing internists, we have both cared for many patients with cancer, some of whom were dying. A couple of WMT's friends thought that it must be comforting to be a physician when struck with cancer, because he could better understand his disease and its treatment than most cancer patients. However, the opposite was true: having actively cared for patients dying of cancer brought to mind vivid images of physical and social involution, the inevitable melting away of body mass, disability, pain, and morbid deathbed scenes. WMT was haunted by the vision of a patient with non-Hodgkin lymphoma who died on his inpatient service 2 months before WMT received the same diagnosis. EDM recalls waiting for her first dose of flame-orange adriamycin, sure that it

would kill her because of the awful side-effects of this drug that she had observed during her first clinical rotation as an intern. Her roommate thought of chemotherapy as a powerful, healing antibiotic whereas EDM could only think of it as a poison.

Although we worried about never completing ongoing tasks and reaching our lives' goals, our greatest worries were the effects that our dying would have on our family members. How would our spouses cope with many years of widow(er)hood? How would he or she deal with the kids, the house, school, finances, and other responsibilities alone? Such worries were almost paralyzing and needed to be tended to with many long, difficult discussions.

Inevitably, we could not help but ruminate on, and fear, the process of dying: discomfort, progressive physical disabilities, imagined dying processes (based on our experiences with caring for patients and our own family members dying of cancer), and the slow eroding of one's sense of self. To combat this, we tried to maintain our work schedules and, when possible, hide the effects of our treatments. Editor James R. Cozzarin wrote the following about his mother, who tried hard to maintain her sense of self during her battle with cancer:

I paused, shocked, as she straightened from the open oven, unprepared to face her near-bald pate (hidden these months by the ever-present wig). Disguising my disease, I searched for something to say.

"I remove it when I'm cooking," she explained, "The heat singes the fibers."

"Don't wear it for me," I ventured, "It must get uncomfortable."

"Honey," she said past haunted, too-moist eyes, "I don't wear it for you."

Discomfort

After the shock of diagnosis and thoughts of dying came concerns about discomfort associated with our cancer and its treatments. Henry Fielding (1707–1754) wrote: "It is not death, but dying, that is terrible." And Sigmund Freud (1856–1939), who suffered from oral cancer, lamented, "How long must I continue to suffer in such intolerable pain? When will I be permitted to accept 'sweet peace' or even to ask for it?" The discomforts we feared most were physical pain, both somatic and visceral, and the pain resulting from physical inertia (eg, muscle

and joint pains, decubitus ulcers, nerve impingement).

Similar to other cancer patients, our fear of pain was magnified by the well-documented failure of American medicine to adequately control pain.²⁻⁵ Failure to control pain is multifactorial, but is at least part due to the notion in both patients' and physicians' minds that, somehow, suffering from pain is noble, that long-term use of narcotics results in addiction, and that asking for relief indicates physical, emotional, or moral weakness. We knew that we were not immune to such forces.

Nonetheless, we knew that pain is controllable for most patients with cancer,⁵⁻⁹ and as physicians we knew that we had greater access to pain medications than do most patients. Yet we both suffered from pain during our cancer treatment and feared (and continue to fear) the possibility that increased pain would accompany the recurrence and advancement of our disease.

We also suffered psychological discomfort from cancer and its treatment, including anxiety, depression, and concern for the suffering of others as a result of our disease. Indeed, the most prolonged (and disabling) adverse effect of WMT's treatment has been mild but persistent cognitive dysfunction, including lack of mental stamina and problems with concentration and short-term memory. EDM had to ask her oncologist for psychological intervention when she finally recognized her ongoing symptoms as clinical depression.

Disability

We are what we do? Each of us identifies ourselves to ourselves and to others by our jobs, our hobbies and interests, and our responsibilities. All of these take abilities of various types that were frequently affected by our cancer and its treatment. There were *physical disabilities* (ie, inability to perform our usual physical activities at their usual levels of proficiency, which sometimes led to physical isolation from our friends, colleagues, and patients), *mental and emotional disability*, *occupational disability* (ie, the inability to perform our jobs sufficiently to remain productive), and *spiritual disability* (ie, questioning our faith).

At the time his cancer was diagnosed, WMT ran on a regular basis, lifted weights, and played tennis. By the time of his fifth round of chemotherapy, a computed tomography scan indicated that the cancer was in complete remission. How-

ever, because of his treatment-related disabilities (ie, neuropathy and myopathy), his quality of life was substantially *worse* than when his cancer was first diagnosed. In fact, because he wanted to continue to be active, especially after the myopathy developed, he continued to ride his bicycle by using low gears and staying on flat Indiana country roads. However, because the ataxia caused by his vincristine-induced neuropathy, he fell off his bicycle onto the roadside multiple times, once sustaining a grade III (ie, complete) separation of his left acromioclavicular joint.

EDM has been able to stay active with little physical disability. She suffers more with the emotional burden of living with cancer. She has also found herself trying to make sense of her cancer experience and her heightened awareness of her faith. She has sought refuge and respite by reading the Bible under the covers late at night, a practice that is very new to her. As Peter Gomes wrote in "The Good Book",¹⁰

"If the Bible is understood to be the place where not only others long dead but we ourselves encounter those thin places of suffering, joy, and mystery, and the efforts to make sense and meaning of those encounters, then perhaps we have rescued it from the clutches of the experts and the specialists and placed it where it rightly belongs, namely in the hands of those who find themselves more religious than they thought."

Drug and Other Treatment Effects

Adverse effects of cancer drugs that we experienced were acute (eg, nausea, vomiting, anorexia, weight loss, constipation, insomnia, mucositis, and phlebitis), subacute (eg, alopecia, neuropathy, muscle atrophy, weakness, fatigue, weight loss, and change in body image), and more chronic (eg, fatigue, cognitive dysfunction, anxiety, depression, and even posttraumatic stress disorder). The effects of the cancer surgery that EDM experienced were also acute (eg, incisional pain and reactions to anesthesia, including nausea and insomnia), subacute (eg, change in body image, sexual dysfunction, dysesthesia, and loss of physical functioning), and chronic (eg, lymphedema, loss of joint range of motion, and depression). Adverse effects of her radiation therapy likewise caused acute (eg, nausea, vomiting, and anorexia), subacute (eg, weakness, fatigue, and skin reactions), and chronic (eg, inflammatory response resulting in pain, lymphedema, and musculoskeletal dysfunction).

We suffered through these adverse effects of treatments as silently as we could, not wanting to complain to our providers too much, lest they feel that we were ungrateful for the positive effects of our therapy. We also wanted to avoid appearing to be "wimps." Although we cannot know what goes through the minds of our patients when they suffer from side-effects of the treatments that we prescribe, we both felt that because we were physicians, we should not complain. So we rarely complained about these adverse treatment effects unless we were explicitly asked about them. Even then, we tended to minimize their severity and impact on our lives.

Dependency

As physicians, we were the ones on whom others relied for their well-being and, at times, comfort and consoling. Hence, we found it very difficult to become dependent on others for our personal and professional needs. But our cancers and treatments gave us no choice: we had to be dependent on our family members, friends, and coworkers. Although we hated being so dependent, we found their willingness to help us to be extremely therapeutic, not only physically but emotionally. Moreover, we discovered that others *wanted* to help us, even *needed* to help us to feel that they were doing something to ease our burdens. We came to realize that the therapeutic effects of dependency were bidirectional. We thus sought opportunities for friends and family members to help us, which consequently lowered our internal barriers against seeking and accepting help.

Nonetheless, we also found, as have others,^{11–13} that our cancer resulted in significant adverse effects on the lives of our loved ones who cared for us. It was often physically difficult and mentally stressful for our loved ones and colleagues, regardless of their willingness to help.

Doubt

Not too long after receiving our cancer diagnoses, we experienced overwhelming feelings of doubt and doom. We had no control over our futures and were not even sure we had futures to be concerned about. It was difficult to be optimistic and to carry on activities where the results were

beyond the time horizon of a few months. The resulting feelings of hopelessness adversely affected our ability to focus on the future, and we found ourselves pondering the more negative aspects of our predicaments. We had less energy available to care for ourselves, which may have worsened the physical and emotional effects on our caregivers.

Combating the paralyzing doubt about our futures was *hope*, perhaps the most powerful weapon available to cancer victims. As Emily Dickinson has so beautifully put it:

*Hope is the thing with feathers
That perches in the soul,
And sings the tune without the words
And never stops at all.*

*And sweetest in the gale is heard;
And sore must be the storm
That could abash this little bird
That many kept so warm.*

*I've heard it in the chilliest land,
And on the strangest sea;
Yet, never, in extremity,
It asked a crumb of me.*

Without hope, we were lost and miserable. However, when we found hope to be lacking, it was supplied in abundance by the large network of friends and colleagues that each of us had established during our careers. Receiving short notes by mail and, more frequently, by electronic mail, had powerful (and unexpected) effects on replenishing our reservoir of hope, diffusing our doubt, and improving our outlook and, ultimately, our quality of life. For example, despite knowing his survival probabilities, WMT found it tremendously comforting to hear stories of others who had survived lymphoma to lead healthy, long, and productive lives. This allowed him to continue to focus on his everyday tasks and on the future.

Death

Samuel Butler (1835–1902) said that, "*To die is to leave off dying and do the thing once and for all*" whereas philosopher Corliss Lamont (1902–1995) wrote, "*The wise man looks at death with honesty, dignity, and calm, recognizing that the tragedy it brings is inherent in the great gift of life.*" Although the authors feared the dying process, death itself was another matter entirely. We viewed death as

the absence of both life and suffering, the sudden ending of existence, thought, and possibly the meaning of our lives. In *The Stone Diaries*,¹⁴ author Carol Shields wrote:

Something has occurred to her—something transparently simple, something she's always known, it seems, but never articulated. Which is that the moment of death occurs while we're still alive. Life marches right up to the wall of that final darkness, one extreme state of being butting against the other. Not even a breath separates them. Not even a blink of the eye. A person can go on and on tuned in to the daily music of food and work and weather and speech right up to the last minute, so that not a single thing gets lost.

Death can be many things, depending on the beliefs of the person facing it. It may be the end of all things or the beginning of another life greater than the earthly one. Regardless of our religious beliefs, we knew that death would be a leaving from our loved ones, family, and friends. It would be the end of relationships, shared needs, promises, and planning. Our deaths would leave holes in the lives of people who have shared their lives with us. Consequently, our looming deaths left an emptiness in our own lives because we felt that we would be abandoning those we love. We worried more about what would happen to those we leave behind than we worried about what would happen to us. What happens after death is inevitable and uncontrollable, but we could not help but feel responsible for the suffering and loneliness we would leave in our wakes. Whereas contemplating the dying process was accompanied by sometimes overwhelming fear, contemplating being dead made us feel depressed and helpless, that we would let others down.

Having Cancer Is Not All Bad

Having enumerated what is so bad about having cancer, we must state that having cancer has, in fact, had beneficial effects on our lives. For one, it certainly grabbed our attention. As busy professionals with equally busy families, we tended to live like everyone else—from one task to another, without really stopping to consider the meaning and wonder in our daily lives. Having cancer motivated us to think about what we were doing every day, to prioritize better, and to spend time on those aspects of our lives that are truly important. Some things that seemed important before sud-

denly seemed trivial. Interestingly, as time has passed, we have found ourselves becoming increasingly immersed back into the grind of daily life, losing the perspective we found as cancer victims. We feel as if we are losing something important as we forget the difficult times we had with cancer and its treatment.

Rachel Carson (1907–1964) stated, “*Most of us walk unseeing through the world, unaware alike of its beauties, its wonders, and the strange and sometimes terrible intensity of the lives that are being lived about us.*” Having suffered with cancer, we have tried to take less for granted. Our relationships have become more intense and meaningful, and we and our loved ones have tried to make the most of our remaining time, be it weeks or decades. We have tried, and will continue to try, to give meaning to our remaining time. Having faced death, we have found life to be more intense. *One of our goals is to not lose that intensity over the years.* The cancer, its pain, our suffering, and the threat of dying have intensified our lives and those with which ours are irrevocably entangled.

Love has become more intense and focused since our cancers were diagnosed. Such opportunities are rare, as noted by George Bernard Shaw (1856–1950) in a letter to actress Ellen Terry: “*Man's one gift is that at his best he can love—not constantly, not faithfully, not often, nor for long—but for a moment, a few minutes perhaps out of years.*” Without a promise of later years, we have tried to make those minutes happen here, now, whenever given the opportunity.

In a battle against the possibility that, after death, our lives might dissipate into meaninglessness, we tried to fight through the cancer for meaning. Indian poet Rabindranath Tagore also contemplated his death and how it could give meaning to his life in *Gitanjali*¹⁵:

On the day when death will knock at thy door what wilt thou offer to him?

Oh, I will set before my guest the full vessel of my life—I will never let him go with empty hands. All the sweet vintage of all my autumn days and summer nights, all the earnings and gleanings of my busy life will I place before him at the close of my days when death will knock at my door.

O thou the last fulfillment of life, Death, my death, come and whisper to me!

Rather than fearing his death, Tagore seems to welcome it as a means for recording and validating the meaning of his life. Death offers a time of

reckoning that can enhance the meaning of one's life and one's steps in the great dance of life.

Cancer Survivorship

Our oncologists worked hard to help us survive our cancer. But surviving cancer is not easy either. One of us (EDM) has written of the feeling of loneliness and abandonment that came with completion of her therapy¹⁶:

After my very last radiation treatment for breast cancer, I lay on a cold steel table hairless, half-dressed, and astonished by the tears streaming down my face. I thought that I would feel happy about finally reaching the end of treatment, but instead I was sobbing. At the time, I wasn't sure what emotions I was feeling. Looking back, I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy, and radiation. Ironically, I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned, and terrified. This was the rocky beginning of cancer survivorship for me.

Regardless of whether our cancer therapy would be ultimately successful, we feared being abandoned by the oncology providers on whom we had become dependent not only for our acute therapy, but as a lifeline against the helplessness that threatened to overwhelm us. We live in constant fear that our cancer will recur. WMT has spoken to several friends and acquaintances who have survived cancer and who have been told by their oncologists that they had been cured. *None* of them believed that. The word "cure" is elusive and denotes, in the cancer victim's mind, the state in which there is no chance that the cancer will recur. Every cancer victim knows that the probability of recurrence asymptotically approaches zero, but never reaches it.

Our fear of recurrence has dulled over time, but it's nagging presence will never disappear completely. Both of us know that the original cancer can recur (or, in EDM's case, recur a second time), and we are also at higher risk of a second (or, in EDM's case, a third) primary malignancy. And along with the fear of cancer comes the fear of having to endure another round of treatment.

Nonetheless, as cancer survivors we must get on with their lives and work at rebuilding our interpersonal relationships, which has at times been difficult. Nobody can forget that we are now

cancer patients, someone who has suffered and could do so again. We also have to regain the lost momentum in our professional and personal lives. Getting back into the routine of our jobs has been difficult after realizing that these routines have been driving our lives to an extent that may now be unpalatable. Yet the work is still there to be done, and we must either do it or use our cancer history to make changes in our lives.

As we have attempted to reestablish our professional lives, we have faced the double whammy of (1) not having the physical and mental stamina to perform at the level that we are accustomed to, and (2) not being altogether sure if we *want* to perform at that level. Moreover, because we appear "normal" again, colleagues expect us to perform at our precancer levels, despite our continuing disabilities and doubts as to whether we want to drive ourselves that hard. We feel guilty when we cannot meet these expectations.

Therefore, we are paradoxically striving to regain our normal lives while not being sure we want them, and we now question what "normal" even is. More than 1,000 years ago, Scots believed that a dying warrior's spirit was rekindled into the next child born nearby. Likewise, we will never be the same persons we were before having cancer—that person is gone, and we need to be "reborn" into our new lives, and to use the time remaining to instill meaning and enrichment in our lives through our relationships with those we love.

Final Thoughts About Life With Cancer

We hope that by expressing our experiences with cancer, we will encourage providers of cancer care to better understand what their cancer patients are facing and to help them deal with the "eight Ds." Providers must try to understand the impact of cancer on their patients' lives and the lives of their patients' caregivers. They should focus on both the negative and positive effects of cancer and its treatment, and be as energetic and considerate in treating the cancer patient (and hopefully, survivor) as they are in treating the cancer itself.

There are implications of our experiences, as researchers, for cancer-related research. We are convinced that only patients with cancer can truly understand what it is like to live with cancer and its treatment. Therefore, researchers should involve cancer patients and their caregivers in the

development and testing of treatment interventions and outcome-assessment tools (eg, measures of functional status and quality of life that are specific to patients with cancer).

For those who directly care for patients with cancer, we have this advice: do not just focus on survival! *Talk* to your patients. Too often, you hide your personal discomfort with cancer and dying patients by maintaining distance from them in the guise of respecting their privacy. Instead, we encourage you to become more intimate with your patients' lives and to understand how they have been impacted by this dread disease. You must try to understand what it is like to have cancer, to live with it and be treated for it, and to survive it or succumb to it. Although this will sharpen your skills and empathy, it may increase your own pain and suffering. But there is no other way: embrace the pain and learn from it. Try to achieve a balance between being too aloof and objective (ie, protecting yourself) and being so close to your patients that defeat and death become too painful and paralyzing. Learn gradually, test the waters, and immerse yourself slowly.

Work hard to improve cancer care. Acknowledge what you can do to help your patient and *do it*. Accept what you cannot do, but work hard to expand the limits of what you can do. From your increasing knowledge of what it is like for a patient to have cancer, design interventions that might have no impact on survival but rather improve the quality of life for cancer patients and their caregivers. Test these interventions and incorporate those that work into everyday care, combining scientific rigor with personal kindness. In such a way, scientists will become caregivers who raise the standards of patient-centered treatment for future generations of cancer victims and those who touch their lives.

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