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An Essay on an Authentic Meaning of Medicalization

The Patient's Perspective

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In this essay, the experiences of the author serve as a key to a critical understanding of medicalization in the treatment of cancer in American society. Forms of medicalization described are (a) giving useless treatments to keep the patient under medical care; (b) demeaning and undermining efforts at self-determination and self-care; and (c) keeping the patient's life suspended by continual reminders that death is just around the corner, and that all time and energy left must be devoted to ferreting out and killing the disease. **Key words:** *medicalization*, *medical model*, *self-care*, *self-determination*

IN AN ARTICLE that was published almost 15 years ago,[1] Allan and I took on the formidable task of deconstructing the theoretical, clinical, and empirical underpinnings of the medical model. A great deal of the impetus for my involvement and interest in this topic stemmed from my own treatment in the health care system when I was seriously ill. I swore that if I lived, I would take on personally some of the issues that had so greatly disturbed me while I was a patient. Since that time, I have written a number of articles on the subject of hope, health, and spirituality that describe the obstacles to living, caused by medicalization, that are faced every day by people with life-threatening and chronic illnesses. This essay will be the first that I have developed entirely from a personal perspective.

The absolute economic and social power of medicine increases daily, while its justification continues to be unexamined by the ordinary people who come under its domain, including a very large percentage of nurses. I have 3 objectives for writing this. First, I want to raise consciousness about one of the most cruel form of medicalization one can imagine, the medical control and manipulation as it is experienced by persons with cancer. Second, for nurses who practice in medical fields, but do not choose to question medical methods or authority, I hope that my experiences will serve to remind them of their obligation to protect the rights and dignity of those needing nursing care regardless of whether or not one agrees with their medical decisions. Third, I need something to hand to my health care provider the next time he or she asks me why I do not go for mammograms and the countless other tests that might inform me as to whether or not my cancer, discovered 19 years ago, has roared back with the vengeance that everyone who

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carries this burden learns to dread so much.

Medical prophecies hover over all of us who bear the knowledge that we have a frightful, life-threatening illness. Like demons left over from the day of the dead, dire pronouncements are draped around our necks, heavy as an albatross, placed there to remind us forever of our preordained fate. As a cancer patient, I am continually told, even when I do not want to listen, that I have a horrible thing that I will forever carry inside. I am supposed to think about death, even though all the other people around me who do not have a terminal diagnosis, but will also die, are never encouraged to do so. I am supposed to realize that my disease has me, but is not part of me, something that I do not believe at all. I am supposed to see my disease as a shrouded, alien antagonist. As such, I am engaged with this enemy in an uneven war that I will lose whenever it chooses to close in and open fire on me. In order to shield myself from a surprise attack, I must attach myself with a permanent umbilical cord to my putative saviors in the health care system, and do exactly what they insist, even when it is clear that they have not much to offer. For the rest of my life, no matter how long life goes on, I am supposed to be monitoring it, thinking about it, and giving it my precious time, energy, and life. And this, I have refused to do, much to the consternation of my health care providers who are supposed to be on my side, but clearly are not. Think about it. How much of the last 19 years would I have really lived if I had allowed this degree of medicalization; if I had allowed my life to be ruled by other people's fear of my death.

Cancer patients, like myself and others, encouraged to live our lives in fear and trepidation from what might get us if we are not ever-vigilant, and having long ago lost the ability to decide for ourselves that we are okay, slither fearfully into sterile rooms where we submit ourselves to X-ray machines and other scans in a frantic attempt to reassure ourselves that we are safe for a few months longer. Instead of living our lives, which after all was the whole point of all this, we are either anticipating doctor's visits, getting tests, or waiting for the test results for the rest of our lives. Our fear of death is constantly reinforced as it is thrown in our faces at every turn in the road. Nobody says, "Go out and live your life with abundant energy and joy. Life is short for all of us. Make every day count." Instead, we are encouraged to live from scan to scan. If we decide to skip one, of all the outlandish things, to perhaps take a wonderful vacation, we are told that we are risking our health and have a death wish.

Allan and I warned that the enshrinement of the medical model has resulted in a Medicine that has become so powerful that it has overtaken our lives; that we live in a world in which medicalization is so vast, so enmeshed into the ambient culture, that it is beyond our human understanding and ability to analyze it rationally. The absolute power of medical technology increases daily. Correspondingly, the economics of medical intervention have gotten out of hand in the 15 years since our warning, as medical costs now take large, greedy bites out of the GNP. There is a direct and strong relationship between medical economic power and the ability to force compliance.

All this overexpenditure of money takes place in the midst of a health care system in which most of the diseases that seize us in middle age and somewhat older could have been prevented if our country had a modicum of interest in preventing them. In a much quoted article on the leading causes of death, McGinnis and Foege[2] found that the top 3 contributors to mortality—tobacco, diet/activity, and alcohol—in this country were preventable by behavioral change. Clearly so much life and money could be saved by putting efforts into education and counseling instead of waiting until high-tech tertiary treatments are needed. Bringing up these 3 factors for counseling in a primary care visit could save billions of dollars and many more lives than are saved using high-priced screening tools for early detection.

Instead of a focus on health, diagnostic labeling and technological solutions to issues of human health have taken over medical practice in oncology and other medical fields. People with life-threatening and chronic illness are robbed of self-control on a daily basis. Curing disease has become an end into itself, a battle of life over death that takes no cognizance of the purpose of life, or consequences to the victims of the battle. Death is something to be beaten out of consciousness. It has been said that most Americans believe that death is optional. I do not know about most Americans, but I can testify that most physicians, and more than a few nurses, I have encountered in the last 19 years appear to believe this. What they recommend for victory over death often intrudes into all reasonable efforts at quality of life.

Because I carry a "terminal" diagnosis, and have been a patient in this very omnipotent form of care-giving for so many years, I have had to find ways to protect myself from attempts to control my body, mind, and soul. As a result, I find that I have turned into a person who is very wary and very critical of medicine as it is conceived and practiced, and I am afraid also, that I am very cynical of much of what is promulgated by physicians for care of patients with cancer. This is not a comfortable state of mind to carry around. Given the values of the world in which I live, it is exceedingly hard to verbalize the reasons behind my medical decision-making. I have tried over the years, often without success, to take the best of what medicine has to offer and leave the rest.

To show why I am so alienated from the health care system, I will have to go back 19 years to the University of California, San Francisco (UCSF), where I was lucky enough to be working when my nurse practitioner discovered a lump in my breast. They took out 12 nodes and found that 5 of them were positive. I was lucky because I had a rather unusual oncologist, the last such person I have encountered in this field. He, like me, believed that I should live my life. He was a very remarkable doctor, indeed. He encouraged all my forays into the alternative care world. He gave me what was the state-of the art treatment then, about one-fourth of the chemo that women today get, and then when I decided to leave town to take a position in another city, I told him that I would be foregoing my last few doses of chemo, a decision that he actually supported, at least to my face. As a result of this treatment, I never lost my hair, I was able to work full-time, and I never totally lost my immune system. I just hate what women are going through now—the mammoth doses of chemotherapeutic drugs they must take, in such contrast to my gentler treatment. And women with breast cancer are told that if they want to survive, they better gut up and take it. Tell me, who has ever proved that?

Experiences that occur early in the diagnostic period can lay down the seeds for permanent attitudes toward one's disease and treatment. For me, they were the impetus for the initial lifting of my own consciousness about medicalization. In this article, I will adhere to my own experience, but for 15 years, I have published a Survivor's guide aimed at people with HIV and Cancer that has brought me into contact with a myriad of people suffering serious illness and poor prognosis. I have seen, replicated in the response of so many others, the same themes in regard to medical treatment.

My cynicism actually developed as the result of the improvement in patient decision-making that was promulgated at UCSF, that was so far ahead of its time, in which the patient actually was invited to meet with all the types of physicians who had something to offer the person with cancer—the medical, radiation, and surgical oncologists. What amazed me was how open each of them was in criticism of the other two specialties—while touting what they, themselves had to offer. Some of the openness was because I chaired a large department on campus, and to a great extent, I was treated like a colleague. They all agreed on one thing. No matter what I did, I had almost no chance of living 5 more years. So, I decided right then that I would need to seek out other sources of healing; that I would not entrust my entire future to this defective concept of care that depended so heavily on acceptance of iatrogenesis, and that ignored good health practices in favor of a flawed science that employed a very suspect "gold standard" to prove its worth.

I ran to the vitamin store for advice. I started acupuncture. I learned to meditate and image. I started to exercise. I garnered around me my social support, and changed some aspects of my life that I did not think were right for me. In short, I initiated an alternative health care regime that I have continued to this day. And I believe that this is what has saved my life and my health. I cannot prove it, but it is what I believe most strongly, and I suppose some of the proof exists in the fact that though I am not supposed to be alive, I am.

Cancer to me was a friend that came to me at a time when I was not taking very good care of myself. It was a real summons to heath, and to an examination of my life and death. My health care providers cannot understand what I do for my health or why I do it, no matter how many times I have tried to explain it to them. So, without their help or guidance, I started on a path of learning much about myself and the meaning and purpose of my own life. Over the years I have really accepted that I will continue to live with exuberance until I die, and that when I do die, it will not be an awful, terrible thing, but just another phase in my beautiful life. And, when I die it will be when I am supposed to die, not one minute sooner or later. Many of my colleagues, never having paused to examine their own personal fears of death, reach for pejorative labels like "fatalism" to describe my conception of the meaning of my life.

The notion that I would deplete the precious time I have to enjoy this world in fretting about my upcoming death, or that I would dissipate the only life I have on earth in clinic waiting rooms and doctor's offices—waiting for tests, and worrying about the possible outcomes—because I am so focused on beating the diseased part of my body into submission, and staving off death, is a concept that is terribly bizarre to me now. My own thought about this is, if people with cancer have to worry about dying all the time, why shouldn't we all have to. Why live anyway, since everyone of us will die sooner or later?

It has been so very difficult to exist in two worlds, to have to engage with a world that says, "Enough of all that unproved fakery. Take your medicine." Or, worse: "I know you believe in it, but I don't think that all that weird stuff you are doing is good for you, and it could be very harmful, and could interfere with your treatment." This, almost always said by someone who has not a clue as to any of the evidence that supports the health practices that I rely upon, has never thought about the healing aspects of spirituality for the life or the disease, and has absorbed all the viscous and untrue rumors that run rampant about herbs and vitamins in any health care center, few of which have the slightest basis at all in fact. For example, despite the fact that there have been more than 150 articles showing that in most cases there is a benefit for concurrent cytoxic treatment and antioxidant therapies, oncologists issue blanket warnings to patients that vitamin C and E will interfere with the effect of drugs.[3] This warning appears to be based on one animal study and theoretical reasoning. More important, nobody quite understands that the reason that I maintain my health now is not to fend off death, but because I like how I feel when I am healthy.

I was pressured to make my decisions about treatment within a few weeks after diagnosis. Although I did not know it then, there was no real reason for hurry in my case, as my tumor was not going to rage out of control in the first 10 minutes. I have noted this same "rushing the patient" maneuver so many times since then, a practice that does not allow us to think out clearly what we should be doing. Most of the patients with cancer I have talked with made their decisions very shortly after diagnosis, sometimes while still recovering from the onslaught of the news, the surgery, and even the anesthetic. I have become quite an authority on my disease now, but I knew nothing when I made out my treatment plan. If I had thought rationally about it, some of my choices would have been entirely different. I chose radiation therapy because I liked the radiation oncologist. She was a maternal sort of woman, who talked in a hopeful way about the treatment at a time when I needed both rescuing and a mother. I chose not to have a mastectomy because I could not abide the surgeon, who stood in the doorway, partially turned away from me when he told me about my metastasis. When I started to cry, he complained, "Well this is hard on me, too, you know." I chose chemotherapy because my medical oncologist supported my alternative practices, gave me personal support, and did not overtreat me. Additionally, who in their right mind refuses chemotherapy? All these are very unscientific reasons, indeed. And I think, even then, I understood that none of it would help my long-term prognosis. They kept saying that it would buy me some time while the scientists figured out something else. Nineteen years later, they are still telling patients that.[4]

When I went to radiation therapy, I met some brave and wonderful women in the radiation waiting room for women. My experiences with them shaped greatly my perception of medicalization in oncology. Unless you have a terminal illness, you probably will never hear their voices, because they guardedly shut down the conversation if a professional walks in. Fortunately, one rarely did. I will give a few examples that we ghettoized cancer patients shared that were so unequivocally unprofessional that they have been singed into my very cells. Jean, who was a professional writer, had small cell lung cancer that had metastasized to the brain and had invaded her chest. She sat in the waiting room, breathless, but strangely energetic. Mimicking the hostile tone used by her physician, she told us all what happened when she refused to have chemotherapy, but elected to go on with radiation to the brain. I think all the readers of this journal will know that there was no medical treatment for what she had. Her oncologist gave her 2–3 months to live, with or without treatment, but became so furious at her when she refused chemotherapy that he stamped out of the room. When he reached the door, he turned around and exclaimed, "Your behavior is suicidal. Any rational person would want treatment. What training do you have to make this decision? How would you know whether it will help or not?" Jean gulped silently to herself, "Well, I know because that's what you just told me a few minutes ago."

Jean reasoned that if she was going to die in 2 months anyway, she would rather not die hurling her toenails. How strong she had to be to maintain her stance in the face of her angry and controlling doctor. Notwithstanding, she was very worried about offending him, and felt quite bereft, as now she was wondering who would be available to help her when she needed medication to alleviate pain and discomfort. This is one of the more blatant, persistent, and cruel forms of medicalization, and unfortunately, in my experience, not a rare one—using power to keep a patient under medical care with the administration of highly toxic drugs that have no demonstrated therapeutic effect at all. Even a research agenda was lacking here. This *treatment* would have resulted in the most extreme suffering for the patient one can imagine. After telling Jean that she had 2 months to live, why not send her out to live the rest of her short life with whatever peace she can find? Or better yet, why not offer it, if he must, and then accept her decision. Or even better yet, why not refer her to someone who can help her through her grief and shock? I think perhaps that deep inside, each of us understands medicalization on the very authentic level that it takes to discern the answers to these questions. What is also self-evident is Jean's very uncommon gumption. I do not think that most people would have her demonstrated strength to resist such outrageous pressure. If patients refuse conventional treatment, they should not expect that a great many people will support this decision, in spite of the multitudinous material on the patient's right to self-determination, and despite the lack of scientific validity for some of the treatments being offered.

All this made Jean very angry, but I thought, too that her anger was keeping her going and looking for other solutions. One day we were sitting in the radiation waiting room, a motley bunch of walking wounded, each looking worse than the last, as our appearances reflected the ravishes of our various cancers and our treatment, but all excitedly discussing a paper by Cameron and Pauling[5] that Jean had brought in. They described a study they had conducted on vitamin C therapy for persons in advanced stages of cancer that showed, despite all the misinformation one hears in the medical field, that it is not dangerous, and could improve longevity and support a better quality of life. Some of us were taking it already. I was taking large doses with the complete approval of my oncologist. One of the graduate students in the oncology nursing program walked in to the middle of this conversation, and when she overheard what we were discussing said dismissively, "Well, you all have very expensive urine, don't you." That took the wind right out of our sails. It got so quiet. I held my breath, hoping that her callous and thoughtless remark would not reduce to ashes Jean's spirit, and the spirit of the others, as it had mine, for at that stage we were all very scared and quite vulnerable. Now I would just turn a cold eye on her, and say in an insolent tone of voice, "I did not hear anyone asking you for your opinion, and by the way, this is a private conversation." But that day, I just sat there, feeling very defeated, sadly dejected, and terribly ashamed that I was a nurse, too. I suppose from that nurse's lofty position, all our little pathetic attempts to live awhile longer looked rather amusing.

Since that time, I have heard dozens and dozens of remarks like that from health care professionals that were intended to undermine efforts at self-care and self-determination and bring us back in line. This is medicalization on a very real, a very personal, and a very destructive level. You personally may not believe that antioxidants, exercise, meditation, imaging, prayer, acupuncture, and all the other alternative efforts at health are helpful in terminal illness, but clearly they are not harmful, and they induce a state of well being in patients that is valued among those of us with a grim prognosis. Whether they cure us or not, they allow us to have a purpose, to play a part in our own healing, and they bring about a clarity on our illness and at the end of life that is vital for our peace and comfort. Moreover, the body is ours. Not the doctor's. Not the nurse's. But the medical model, like an insecure, jealous, and controlling lover, takes as a threat to its very existence even a hint that a competitive, and God forbid, more attractive source of healing might steal in to entice away the patient. That is why we are rushed into hasty liaisons with treatments about which we know nothing, and that is why we are supposed to forsake all others. And so the medicalization directive is unequivocal: "Because you have a disease, we own your body and we control your treatment. We and we alone have the right to decide what is proper care for you, because we know everything that you need to know. Do not do anything unless you clear it with us first. We are the authority on your disease, so please do not confuse everything by collecting information for yourself. That is our job. And please do not think for yourself or try to evaluate our recommendations. We know exactly what we are doing."

After 5 years of follow up, I had enough of being a cancer patient, and decided to fire my new oncologist, and trust solely in my own methods of healing. Because he was an internist, too, he had offered to be my primary care provider as well as my oncologist, and I had readily accepted. But over time, two things bothered me greatly about the way that he medicalized me and eroded my confidence. First, he continually reminded me that I was always in danger of death—that I was in a very precarious position in regard to a recurrence. If I had a small headache or a backache, the same kind that anyone has occasionally, I would be sent for a scan, and told that the high probably was that my cancer had metastasized. The weeks that elapse while waiting for appointments and for the results of scans to get back to the doctor is interminable to the anxious patient. Frankly, I could not live like that. In fact, I decided that if that was how I had to live, I would rather die.

The other thing that sealed my decision was that I had to have a chest x-ray, blood cancer-screening tests, and mammogram every 6 months. I learned to dread these visits and the long periods of waiting for results after the tests. Thinking that I had my fears of recurrence in good control, I would just go about living my life for a few months, and then it would be time to stir up the fear again. So I finally decided after much thought and discussing it with friends that I would just begin to live my life and stop fretting about whether I would live into old age, or if death were just around the corner. I had also pretty much decided that I would not allow myself to be cut up again in surgery. I would never take another dose of chemotherapy, nor have radiation again. So I reasoned that if no treatment plan rested on the results of mammograms and other tests, what was the purpose of having them? People ask, "Don't you want to know if your disease has returned—if you are going to die soon?" No, do you?

I have held fast to that decision through a barrage of criticism and deprecation over the last 14 years that I cannot even begin to describe to you. I still have yet to find a medical provider who is comfortable with my decision, and who does not have to teach me, lecture me, ridicule me, or challenge me. Worst is when they talk to me like I am 3 years old, and try to explain patiently, to this exceedingly tedious nurse, who after all should be better informed, why I need to put myself back into the round of scan anxiety. They are especially shocked that I have not had a mammogram in many years. They go over the American Cancer Society mammogram recommendations with me in such baby talk that I feel like replying, "Gee whiz, when did they decide that women should have mammograms?"

The notion that you live, really live, until you die is so totally lost to medical reasoning. I am expected to join the ranks of those who are forever doomed if they are not careful. The medicalization directive says: Once a cancer patient, always a cancer patient. Except I have declared, to everyone's extreme discomfort, that I am no longer a cancer patient. My position on medicine is a real threat to the system. If left unchallenged, it could grow to undermine all the fictions we have learned to accept as good, proper, right, and true. As a result of my bad attitude, I cannot go to a physician for care. The last one I went to held me such hostage that she would not release to me the results of my cholesterol screening until she saw that I had gone for a mammogram. So, I did not return to her practice. The "doc in a box," in the shopping mall is available to treat a bladder infection and other small things, and they could not care less about my medical history.

Occasionally, I reenter the medical field when I want screening bloodwork, or I have a few complaints that are not related to cancer that I want examined. When I do, I endure lectures from my providers on the subject of my lack of attention to my cancer. Trying to be partially in the health care system is like trying to be a little bit pregnant. Being away for awhile, it is easy to forget how incredibly encroaching medicine is; how much it engulfs the lives of patients; how it moves in so quickly to assume its proper place as resident authority on what we should be doing or not doing with our own care; how shamefully narrow is its focus on curing incurable disease; and how much it discounts health and preventive practices.

CONCLUSIONS

As I read over what I wrote above, part of me noted that I had been very hard on medicine, and the other part said that it would be impossible to be too hard. It is true, however, that medicine cannot bear the sole blame for the sorry disarray of health care in this country. There would be no medicalization if we lived in an economic system that did not condone, even promote what medicine does. It is very hard to know if medicine is a leader or a follower.

My opinions on how much seriously ill patients who come under the restrictive and myopic yoke of biomedical practice suffer have been developed from a tremendous amount of informal evidence gathered from people with life-threatening illness, such as cancer and HIV. The truth is that many professionals probably comprehend medicalization from a personal perspective, because they, or a family member, have experienced it. Anyone who has a chronic disease understands it, but somehow we shrug it off and let it continue. I have been guilty of that, too. Needed is a lifting of the false consciousness that informs us that their are no possible solutions to medicalization and the misuse of health care moneys. There have to be solutions, and I think some have to come from the profession of nursing.

What is clear to many of us in more health-oriented fields is that the biomedical model indisputably is getting out of hand. Drugs with life-threatening side effects are being touted directly to consumers. Little research money is targeted to preventative and health-oriented research. The money that is spent on prevention is spent on secondary prevention, or early detection. We are told that mammograms save lives, but how many lives could we save if research funds were targeted to primary causes of cancer and heart disease.

We have lost our concept of primary prevention. We have accepted the obfuscation that early detection is the preferred form of prevention, and is where we should be putting our efforts. This view fails to take into account that any disease is better prevented than detected at any stage. When people incur enough tissue damage to have a diagnosis of disease, even if it is caught early, the chances affecting a cure are small, and the available medical solutions invariably are, in themselves, harmful to the body. Moreover, having an early detected disease is as much, if not more, medicalizing than having a late-stage illness. Treatments for early diseases are often quite radical and harmful, and worse, they tie one into medical care for the rest of one's life. A drawback to prevention, from a health industry point of view, is that it relies almost totally on self-care efforts, and if an illness never occurs, one is never brought into contact with a medicalizing health care system.

From my own experience and that of many patients I have counseled, many medical treatments offered are not in the best interest of the patient. They do not prolong life, and they have severe and dangerous side effects. But Gadow[6] in her treatise on existential advocacy affirms that the right to self-determination should be preserved even if the patient's decision is not in the best interest of health. Health is only one of many values that need clarification. Patients need an opportunity to be fully informed about options, then all relevant values, not just those concerning treatment outcomes, need to be examined and brought to light before a final decision is made.[6] The more protracted course of existential advocacy flies in the face of the common "hurry up and decide now" process of medical decision-making.

In practice, I hope nurses will examine their behavior to see if they are contributing to patient medicalization. At very least, anyone can learn how to be quiet and listen respectfully when talking to patients about medical decisions. Believe me, if patients have had the diagnosis for a long time, they probably know more about it than you do, and in ways that you could not possibly understand, unless you have been there. Every time we look at our scared bodies, or remember the taste of toxic drugs in our mouths, we are reminded of the struggles that we have gone through and what we have had to endure in order to survive cancer.

Finally, I have not touched on a related issue, the victim-blaming that accompanies the diagnosis of cancer, which most cancer patients know about first hand, and take on as a personal rebuke that furthers lowers self-esteem in this defenseless population. It is so outrageous and incessant that it could be the subject of another entire essay. Ken Wilber, the internationally known psychologist, after the death of his wife, Treya, wrote a book[7] on her experiences in living and dying with cancer. Wilber used Treya's words to describe the humiliation of having a disease in which everyone has a pet theory about why she got it—psychological hang-ups, emotional problems, did not take care of herself—pick one. Furthermore, people who could not possibly know what they were talking about all had an answer to not only what caused her cancer, but what she needed to do about it. So, it is not only the health professions that medicalize. Medicalization is a societal phenomenon and a form of horizontal abuse that pits the well, or those whom I like to call "the not-yet-diagnosed," against the sick.

I hope that having just this very brief glance at an insider position will create an impetus for reform. Nursing is inextricably linked with medical practice. While nursing theory development has favored patient-centered concepts, such as caring, the care takes place in a medicalized health care environment with medicalized patients. Consciousness about medicalization is sadly lacking in nursing. I hope to wake up one morning and learn that people in my own field are now focusing their full attention on life, spirituality, hope, and health, and that these considerations have finally assumed, in all of health care, an importance at least equal to all the attention now given to promoting vigilance and fighting disease technologically.

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