

## Hall's Authentic Meaning of Medicalization: An Extended Discourse

By: Richard W. Cowling III, Mona M. Shattell, and Marti Todd

[Cowling, W.R.](#), [Shattell, M.](#), & Todd, M. (2006). Hall's essay on an authentic meaning of medicalization: An extended discourse. *Advances in Nursing Science*, 29(4), 291-304.

Made available courtesy of Elsevier: <http://ans-info.net/>

**\*\*\*Note: Figures may be missing from this format of the document**

### **Abstract:**

The purpose of this article is to inform emerging theoretical understanding of medicalization by challenging, updating, and affirming a previously published essay on this topic by Hall. We accomplished this through the creation of a discourse among the 3 authors using the essay, written entirely from a personal perspective, and integrated our own personal experiences as nurses and patients. Hall's essay on the authentic meaning of medicalization provided a critical understanding of medicalization of cancer describing the factors, forces, and consequences, seeking to raise consciousness and provoke reform. The 3 of us added our voices to her narrative seeking to expand the discourse on medicalization and inform theory development. We have shared our individual and collective voices and identified elements that might point the way to theoretical emergence and ending with our own call for nursing to evolve further as a field worthy of human inspiration. Keywords: cancer, dialogue, discourse, medicalization, open heart surgery

### **Article:**

The purpose of this article was to respond to the *Advances in Nursing Science* call for challenging, updating, or affirming previously published work as an endeavor aimed at informing theoretical development in the area of medicalization. We created a discourse among ourselves focused on Hall's essay on the authentic meaning of medicalization, the first she had developed on the topic entirely from a personal perspective.<sup>1</sup> We regarded her work as a unique and salient expression of a harmful and prevalent situation in healthcare and sought to raise our awareness, individually and collectively, in response to her calls for attention. We believed in the power of participatory knowing—a type of knowing that emerged from dialogue among ourselves, with others, and with Hall's narrative—and its potential for grounding our discourse. Our ultimate goal was to use knowledge generated from this discourse to inform theory development associated with medicalization.

Hall described her 19-year journey since her diagnosis of breast cancer and shared her experiences and perspectives to provide a “critical understanding of medicalization in the treatment of cancer in American society.”<sup>1(p53)</sup> She highlighted at least 2 major forces in the medicalization of cancer: fear as a force for control and the enshrinement of the medical model. In Hall's experience, medicalization took the forms of “(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 the time and energy left must be devoted to ferreting out and killing the disease.”<sup>1(p53)</sup>

Hall sought to raise consciousness about the cruelty of medicalization for cancer patients, to remind nurses of their obligation to protect the rights and dignity of those needing care, and to create something she could give to healthcare providers to help them understand her perspective.<sup>1</sup> She provided a compelling account of her experiences of being diagnosed and treated, highlighting the consequences of the medicalization of her situation. Her account included reflections regarding what she thought was best for her health and well-being, her desire for self-determination, the responses of healthcare providers, and the impact on her life and those of other people living with cancer.

Hall yearned for reform—for the insider position illustrated by her story to invoke change.<sup>1</sup> She acknowledged the inextricable link of nursing to medical practice and that in spite of its commitment to patient-centered concepts, care occurs in medicalized healthcare environments. She decried the fact that consciousness about medicalization is depressingly lacking in nursing. Hall longed for a time when people in the nursing field would focus “their full attention on life, spirituality, hope, and health”<sup>1(p62)</sup> and that within the entirety of healthcare, these are given consideration at least with the same intensity that now is given to “promoting vigilance and fighting disease technologically.”<sup>1(p62)</sup>

It was our hope that this discourse would affirm and broaden the authentic meaning of medicalization presented by Hall through consciousness raising, bringing attention to alternatives to medicalization in nursing, and promoting further discourse on the potentials for change and reform. We believed that this discourse should build upon our personal experiences both as nurses and patients consistent with Hall's approach to critical understanding and further explicating the insider position through our voices. We realized that our reactions to Hall's article were created from our own life contexts and experiences interacting with her story and sought to be consistent with Hall's desire for authentic meaning—we deemed it important to enrich theoretical understanding.

Hall noted that many professionals probably comprehend medicalization from a personal perspective owing to their own or their family member's experiences.<sup>1</sup> The 3 of us are nurses. One of us had recently experienced endocarditis and successful open heart surgery for mitral valve prolapse and one of us is living with cancer. Our responses to Hall's story and her perceptions were varied and reflect the contexts of our lives as consumers of healthcare and as nurses.<sup>1</sup> The ideas that Hall described were important orienting points for our initial reflections and responses. We also developed our own ideas integrating our experiences and reflections with her ideas of fear, enshrinement of the medical model, useless treatments, undermining self-determination and self-care, and reminders of death.

## RICHARD'S VOICE

### *Fear as a force for exerting control*

Hall attributed fear as a major force in healthcare to medicalization of cancer.<sup>1</sup> She described how “medical prophecies” hover over patients who are being treated. “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.”<sup>1(p54)</sup> Fear was used in a variety of ways that had direct impact on Hall's life and also on other patients whom she came to know. It was used to encourage her to make treatment decisions early after the initial diagnosis even when she was not ready and, as she later learned, it was not necessary. Fear became a motivator to make her compliant to the wishes of her healthcare providers. It became clear that if she were responsible as a cancer patient she would continually be monitoring her condition in a vigilant way. It was also a major factor in getting her to buy into certain treatment approaches. Hall described this as allowing her “life to be ruled by other people's fear of her death.”<sup>1(p54)</sup>

Mitral valve prolapse was my diagnosis and it had some different features of fear than cancer as described by Hall, yet fear was a pervasive experience. I was given the diagnosis during an echocardiogram procedure after a concerned technician left my side suddenly and returned 10 minutes later saying she was seeking a doctor to look at the images on the computer screen. They discussed the severity of the condition as if I was not present and then he presented me with the diagnosis. He described severe regurgitation in my heart that would have to eventually be treated surgically. He also warned me that if I had surgery too soon or too late there would be negative consequences. He and the technician then told me I was free to go. Two days later I was contacted by a cardiac surgeon's office to schedule an appointment. This was another shock because when I had spoken with my primary care physician, he had helped me understand the diagnosis and reassured me that surgery was not immediately needed and that I might be able to live with very minimal medical intervention. The referral to a cardiac surgeon was a mistake in the system and subsequently I was referred to a cardiologist. However, surgery became a predominant fear.

From the first diagnostic proclamation by the technician, fear was a dominant force in my life. Fear was experienced as within me and beyond me—internal and external simultaneously. Some of the fear arose from my own lack of knowledge and preconceived notions about the potential for surgery or death. Some of the fear arose from information and misinformation given to me by healthcare providers. There were many incidences in which healthcare practitioners questioned intensely the absence of symptoms normally associated with the type of echocardiogram films that were produced in diagnosing my condition. There were times when I anticipated the symptoms or found myself wondering when the symptoms would present. I was also reminded, like Hall in relation to her mammograms, that I should have an echocardiogram every 6 months to monitor any progression in my condition. I anticipated each examination with fear and dreaded the wait for the final results.

With mitral valve prolapse there is some disagreement or misunderstandings among medical practitioners about the best course of treatment. The first cardiologist I met with told me that if I took care of myself, exercised, lost weight, and lowered my blood pressure, I would not need to have surgery or I might not be required to have surgery until I was in my seventies. However, another cardiologist suggested I seek information about surgery and I learned that the current thinking is that surgery before cardiac deterioration is recommended. I decided to have surgery and was able to have a mitral valve repair rather than a valve replacement. The uncertainty about the best course of action was at times overwhelming.

In some cases, my experiences with alternative and complementary practitioners evoked fear. This took the form of suggesting that I might be more cautious about choices for treatment in the mainstream healthcare system. One practitioner had negative impressions about surgical intervention that he shared with me. However, most of my experiences with alternative and complementary therapy practitioners resulted in an easing of fear and learning ways to ameliorate my fear, including strategies for self-protection, when dealing with the healthcare system. Alleviation of fear also came in the form of being able to share and process these fears.

Hall described the ways in which fear associated with medicalization was used to encourage compliance or selecting a particular treatment.<sup>1</sup> In my case, only 1 cardiologist used warnings and dire prophecies to promote his treatment agenda. He also prescribed a medication for elevated blood pressure, which I later discovered was unnecessary. It also had very severe adverse effects. However, because of my fear of surgery I continued to take the medication for 2 days in spite of very severe headaches. I overcame my fear when a colleague suggested that I had the option to not take the medication. This led to my speaking with my primary care physician, who supported me in taking a nonpharmacologic approach and securing a new cardiologist. Compliance in taking antibiotics before dental care and any invasive procedure was also prompted by the fear of endocarditis, which eventually occurred in spite of taking those precautions.

Another experience that Hall reports in relation to fear was rushing her to make decisions about treatment early in the diagnostic process.<sup>1</sup> In my case I experienced this with the doctor and the technician who performed and evaluated my first echocardiogram. They warned me to take action and at the same time warned that the timing of a surgical intervention would have potentially critical consequences. In addition, they made a referral to a cardiac surgeon prematurely and without my consent, although this was described as a mistake.

### *Enshrinement of the medical model*

Allan and Hall warned of the enshrinement of the medical model that would become so powerful it would overtake personal lives.<sup>2</sup> Medicalization is so vast and pervasive that it is part of the ambient culture, making it extremely difficult to analyze. It has also been accompanied by costly medical interventions that overwhelm the general economy. Hall noted the “direct and strong relationship between medical economic power and the ability to force compliance.”<sup>1(p54)</sup> Medicalization with its economic impulses toward greed has helped create medical practices based on victory over death rather than on human health.

In terms of her personal life, Hall delineated a 19-year experience since her cancer diagnosis fighting to protect herself from control and finding that she had become cynical about medicine as it is currently conceived and practiced.<sup>1</sup> She found it exceedingly hard to verbalize the rationale for her medical decision making. Hall detailed the journey she had taken and related the evolution of her perspective through experiences in the medical care system and with healthcare practitioners.

Hall attributed her rising cynicism to the promulgation of patient-centered decision making at the medical center with which she was associated.<sup>1</sup> She also experienced open criticisms of one specialty toward another to which she was likely privy because of being treated as a colleague.

They all agreed that regardless of her efforts, she would live no longer than 5 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 on iatrogenesis, and that ignored good health practices in favor of flawed science that employed a very suspect ‘gold standard’ to prove its worth.”<sup>1 (p56)</sup>

Unlike Hall, my cynicism existed before my diagnosis owing to my personal as well as my educational, professional practice, and research experiences and endeavors in the field of unitary science.<sup>3</sup> I had also collaborated with Peggy Chinn and Sue Hagedorn to write a manifesto for nursing that was part of a Web site project.<sup>4</sup> This manifesto voiced our concerns about the clinicalization and medicalization of nursing. Thus I was primed to go beyond the medical practitioner's advice and seek the help of others who had less than traditional medical values and beliefs. My journey included sessions with Reiki practitioners, advice from my spiritual guide, use of herbal remedies based on recommendations from people with similar needs, and 5 sessions of psychic surgery with a Filipino healer. In addition, I had many friends and colleagues in the holistic and unitary fields who taught me meditative and imagery practices for my heart and in preparation for surgery.

Attributes of the enshrinement of the medical model based on my experiences and consistent with Hall's described experiences are persistent.<sup>1</sup> Medical practitioners decide what counts as evidence, what is scientific, and what is rational regardless of the patient's perspective. Authority and expertise are located within practitioners, not patients, and the role of these practitioners is to direct the care of the patient and evaluate their choices. An example that highlights these 2 attributes from my case was being told by the cardiologist who performed my cardiac catheterization that the openness of my arteries and absence of plaques had nothing to do with my vegetarian diet but was attributed to genetics, in spite of the fact that my father suffered from coronary artery disease. The value of alternative modalities and spirituality and hope, if acknowledged at all, is minimized by most healthcare practitioners. I lived a clandestine healthcare existence where I used alternative and complementary approaches—not sharing any of these with my medical care providers. Another attribute is the early treatment of diseases that might be more radical than necessary. In my case, as described previously, the doctor involved in my case prematurely wanted me to consider surgery. Finally, another attribute of enshrinement of the medical model is offering medical treatments that are not in the best interest of patients. This occurred for me with the prescribed use of nitroglycerine to lower my blood pressure when there were drugs that were more effective and with fewer side effects, and in dismissing the use of an herbal remedy that I have found effective in lowering my blood pressure.

#### *Useless treatments prescribed to keep a person under medical care*

Hall described the distinctions in medical perspectives concerning the chemotherapy dosages required to treat her cancer.<sup>1</sup> Because she had an oncologist who encouraged her to use alternative care modalities and had a state-of-the-art approach to chemotherapy, using smaller doses and supporting her decision to forego some of the doses. This gentler treatment meant no loss of hair, support of her immune system, and ability to work full-time. Hall noted the mammoth doses of chemotherapy many women are required to take that lead to negative consequences. In many cases, women are told they must take these doses to survive, even though this is not fully proven.

In my case, I was not given any treatments that I would consider useless. This may very well be associated with the nature and type of condition. My condition was a functional problem that is best treated by surgery. The medications used to treat the symptoms are nowhere near as toxic as chemotherapy. However, the treatment of elevated blood pressure with medications that are fatigue-producing is a difficulty that was never addressed by my medical practitioners. I learned about these consequences through a colleague who specializes in cardiovascular conditions. In addition, there is little or no inclination to consider herbal or other more natural alternatives for control of hypertension that have little or no toxic consequences and that do not induce fatigue.

### *Demeaning and undermining efforts at self-determination and self-care*

Hall experienced a variety of efforts on the part of her medical practitioners, including nurses, to demean and undermine her efforts at self-determination and self-care.<sup>1</sup> She also observed this with other patients who were dealing with the same diagnosis. Power was used to keep patients under medical control. She provided poignant examples of demeaning and undermining behavior from both nurses and doctors. In one case a woman who decided not to have radiation therapy, because she only had a few months to live, was told she was irrational and that her behavior was suicidal. In another example, an oncology nursing graduate student chastised a group of patients having a conversation about published studies about vitamin C therapy by saying they would have very expensive urine. The consequences of these experiences is often demoralizing to the patient and his or her family as well as patients guarding what information they will share with their healthcare providers.

In my experience, I did not put myself in these situations because I refused to share information about the alternative and complementary approaches I was employing. In particular, I was convinced that my healthcare providers would not understand approaches based on spiritual connections and powers. Although a powerful guided imagery was employed systematically before surgery that I am convinced enhanced the outcome of the surgery, I never shared this with any of my healthcare providers. My spiritual guide, with whom I have worked for several years, taught me strategies to protect myself and my heart from negative and fearful thoughts and energies in the medical care system as a whole. She also suggested that I not share my fears or my positive thoughts with anyone who thought negatively about my prognosis. I was very careful not to share information about my condition with colleagues who operated from a primarily medical and surgical understanding of heart conditions.

### *Keeping the patient's life suspended by continual reminders of death*

Hall provided compelling examples of medical prophecies used to remind her and others of the frightful and life-threatening illness with which she must live.<sup>1</sup> Most notably, she felt as if she were at war with an enemy—a war she could not win. Hall was told that for the rest of her life she was “supposed to be monitoring it, thinking about it, and giving it [her] precious time, energy, and life”<sup>1 (p54)</sup>—her life “ruled by other people's fear of death.”<sup>1 (p54)</sup> Hall notes that cancer patients are encouraged to live their lives in fear and trepidation, being ever vigilant—“anticipating doctor's visits, getting tests, or waiting for test results”<sup>1 (p54)</sup> and “living from scan to scan.”<sup>1 (p54)</sup>

For me, I did not experience the same intensity of life suspension as Hall's experience, I think owing to the differences in our conditions.<sup>1</sup> However, with the requirement that I have an echocardiogram to monitor the potential progression of the effect on my heart of the mitral valve prolapse, I lived in anticipation of what might be found. I constantly worried about doing what was right to avoid the potential of further damage. I was also warned that I could get endocarditis from any invasive procedure, even tooth cleaning, and prophylactic antibiotics were prescribed before any such treatment. Eventually, I did get endocarditis, in spite of following the prescribed regimen of antibiotics.

#### MARTI'S VOICE

After reading Hall's article, it is easy to feel anger about medical providers and their treatment of individuals with diseased bodies; however, that has not been my experience.<sup>1</sup> June 2006 was my 5th birthday since the diagnosis of ovarian cancer. I use the term birthday to signify a “new birth” representing my new-found choice to focus on better living. Since I was diagnosed, I have had multiple treatments—8 surgeries, 4 rounds of radiation on 4 different parts of my body, and 2 series of chemotherapy. I have invested time and energy in prayer, meditation, herbs, dietary changes, exercise, and various strategies in pursuit of mental/emotional health. It saddens me that traditional and alternative treatments for healthcare are not equally considered by medical practitioners.

#### *Health and wellness*

I remember feeling hot humiliation rising in my cheeks as people who knew me stared at me once they knew I had a cancer diagnosis. I shaved my head to avoid the mortification of losing my hair. I refused to wear a wig even when all my hair was gone. I prided myself on my appearance as shame flew over me. My husband, who was far wiser than I, whose heart was filled with compassion, said to me, “Ma belle, you will wear the wig and you will go someplace every weekend with me—where no one will know you have cancer and you will behave like a normal human being ... interact, live, and be real.” It was one of the best things anyone did for me and became the beginning of an inward journey toward the highest level of health and wellness, in the face of a new diagnosis and losses within my body.

Recently, when I told my radiologist about having an ION foot treatment, I realized he had not heard of it—he did not know about the overall health benefits of ION foot treatments. In addition to improvement in my overall health, ION foot treatments remove cells that should not be in certain parts of my body. My ovarian cancer cells travel through my lymph nodes and blood supply. I have had ovarian cancer tumors in the abdomen, brain, blood supply to the heart, liver, and lung. If some of the ovarian cells are removed thru the ION treatment, I consider it a success. I also consider it a success if my general body health is improved.

My doctors (oncologist, radiologist, neurosurgeon, and generalist) were all unfamiliar with ION foot treatments and are not aware of any of my other choices to promote best health. I shared all information regarding my alternative treatments and educated them if they asked questions. I encouraged them to see health and wellness as much more than just healing the body. When my oncologist last saw me, he was so impressed with my awareness and actions related to health that he encouraged me to help other patients by volunteering time through the hospital. Through this discussion and others, I ask them to redefine their definition of health. I tell them that I use every

part of myself—body, mind, spirit, and faith—to move in a positive direction toward healthy living.

I encourage my doctors to review other definitions of wellness since I believe their understanding has been misinterpreted by the traditional Western medical model. My physicians have been supportive of my perspective. I believe that intention, desire, and thought in body, mind, and spirit help me to achieve health and wellness. I believe that the ability to use my mind, body, and spirit contributes to me and others. I have been encouraged by my oncologist to help others take this path with hopes of arriving at this place. To pretend that I have not had sadness, sorrow, and difficult moments is not true. I made a conscious decision to allow the anger and sadness to be felt briefly as my time and energy and positive feelings were better focused on a path to wellness. My body works much better when I save my energy and think about wellness.

I am clear in my relationships with my doctors that I expect them to work with me in a partnership, and that all treatment options will be my choice. My doctors have been incredible to work with in this respect. My doctors work hard to explore options and provide ideas, all from the traditional medical model. They clearly communicated treatment options and discussed options of what would provide the most healing of my body as well as potential consequences on my body. We held respect for each other in these active discussions. Unlike Hall, I do not expect them to know and recommend alternative therapies.<sup>1</sup> They are amazed at my health even in the face of this disease in my body.

Hall said, “I have had to find ways to protect myself from attempts to control my body, mind, soul ... I am very cynical.”<sup>1(p55)</sup> I did not presume to be at war with the medical system. I made the decision to expect them to join me in search of healing body parts as there were many aspects of wellness in existence already. Hall's anger was evident in statements such as “medical prophecies hover over us,” and “continually told ... of a horrible thing that I will forever carry inside.”<sup>1(p54)</sup> I suppose my own view is more consistent with the medical model in that I believe that the discovery of tumors earlier allows for kinder treatment of smaller spaces in my body. Hall stated, “No one says—Go out and live your life with abundant energy and joy.”<sup>1(p54)</sup> I was fortunate that my doctors were clear to encourage this very kind of thinking and action.

I have often wondered and disliked the expression “fighting cancer.” I do not feel like a warrior, nor do I want to become one. Visioning me as a fighter does nothing but churn emotions; it evokes images of winning and losing, death and destruction, a world war inside my body. Being on a journey in my life where I seek options for health and wellness suits me. I encourage nurses to ask patients what their image is that helps them to arrive at that journey toward highest health and wellness. Acknowledging our internal monsters is a way to know who you are and to calm the beast within. For nurses to consider this and also encourage patients to find this part inside them promotes better solutions and actions toward health. This concept is called total surrender in trauma work.

Trauma, which can be defined as bodily or emotional shock, often occurs when news of a diagnosis is delivered. At the point of diagnosis, nurses have an opportunity to help patients identify the best skills they have to recover, cope, and maintain the highest emotional and physical response to the disease. Tension will have no home within thoughts and action if we

look within. There is a peace that we all seek within ourselves and it is not found in investments in idolatry of self, fear of the future, war with others, or slave to the present. Inner peace is experiencing the world with sight, sound, communication, and feelings that contribute to healing.

### *Life and death*

The issue of cancer and dying is mentioned many times in Hall's article 1 as an aspect that doctors mention to patients: "People with cancer have to worry about dying all the time. ... Why shouldn't we all have to?"<sup>1(p56)</sup> People without cancer do worry about this as I have witnessed in my work as a psychiatric mental health nurse. Those I have met socially who focus on death just seem to choose this as a pastime. Even Hall says "Live with exuberance until I die, and then when I do die, it will not be an awful, terrible, thing, but just another phase in my beautiful life ... not one moment sooner or later."<sup>1(p56)</sup> While contradicting her earlier statements about death, it beautifully describes meeting peace with the meaning of death. Nurses should allow and encourage patients to cope with life and death if it is important to the individual. Peace comes when issues are decided by the patient.

Quality of life differs from one individual to another. My experience is different from Hall's implicit definition of quality of life: "What they recommend for victory over death often intrudes into all reasonable efforts at quality of life."<sup>1(p55)</sup> Did I pay a price for treatment in terms of functioning? Indeed I have, but the gains have far outweighed the costs. I happily accept the time I am given and am at peace with the possibility of death. When I talk with doctors, I tell them I understand and accept the fact that I will die. I used to ask them how long I had to live (they never wanted to tell me). I asked for the potential of clinical trials and also for all the standard treatment options. I wanted to know how long I had to live because I needed to prepare my 2 children. From this experience, I learned that doctors really have no idea about prognosis from person to person because life or death is so individual and in part dependent upon how one lives. How an individual chooses to live, once diagnosed, is within their choice.

### *Partnerships with medical care providers*

I am blessed to have been active in nursing as a staff nurse, nurse manager, nurse administrator, parish nurse, and care coordinator. I do not understand how the layperson can approach treatment without this level of education and work experience. I considered each medical person in partnership with me. I do not assume they have every answer to every question or problem. For the layperson, nurses can educate individuals who approach the medical system on how to develop partnerships with doctors.

Nurses can teach each person to ask for every option so the choice is one that they alone make. I agree with Hall on this aspect, which she makes so clear, that others tried to make decisions for her.<sup>1</sup> However, Hall approached the system and did not seem to shop for a doctor who fit her needs for information, but just went to someone with a title—with no information regarding the style of how that person provides medical care.<sup>1</sup> Furthermore, the person who approaches care should be clear in what they desire: are there treatments in the disease that can lead to wellness—clinical trials, average treatment options, or unusual and challenging options? What are my options if I choose nontraditional treatments but continue to have pain issues?

Personally, I shop for a doctor who will engage in talking, accepts that the patient will ultimately make the decision, and accepts being challenged about what they believe is best. I had to develop this skill and call medical offices to find answers regarding how physicians approach treatment. After answers are given, if they are not acceptable to me, I keep shopping. If they were acceptable, I would follow up with an appointment.

Medical care and treatment offers many more options than it did 15 years ago. Options for me—that have been incredible and positive—are radiation specific to tumors, surgical removal of tumors, entering the skin finding the site of a tumor and “burning” it away, and medications specific to my type of cancerous tumors. The ability to understand more clearly how mind, spirit, and faith contribute toward health has been excellent in the journey to wellness. In my career as a nurse and as a patient, I continue to see improvements in treatment options.

### *My message for nurses and other healthcare providers*

Like Hall, I want nurses and other healthcare providers to use our personal experiences and learn from them: learning that “living well” is critical when one is living with cancer; encouraging individuals to explore traditional and alternative treatment options, including the possible positive and negative consequences of each; and supporting each person's choice.<sup>1</sup> In my experience, nurses and other healthcare professionals could provide more education to inform the person that they have options, including the option to determine the kind of care and level of wellness that can be attained within their partnership with their healthcare providers. The individual patient and his or her choices should be considered number one by all healthcare professionals. Nurses have an important role in this respect. I encourage nurses through Frankl's posttrauma wisdom: “Everything can be taken from a man but one thing: the last of the human freedoms—to choose one's attitude in any given set of circumstances, to choose one's own way.”<sup>5(p75)</sup>

### MONA'S VOICE

As opposed to my friends, colleagues, and coauthors (Richard and Marti), I have had much less experience with the healthcare system, especially as a patient. Even as I write this, it seems preposterous, since everyone living in the United States is exposed, inculcated, and bombarded with the subtle yet all-encompassing medical model. Even I, as I sit down to write, am unconscious of the insidious nature of medicalization. As stated earlier, one of Hall's reasons for writing her article was to raise awareness.<sup>1</sup> Upon reflection on my personal experience with medicalization, I separate myself from my colleagues, to use Hall's term, “not-yet-diagnosed, against the sick.”<sup>1(p62)</sup> I am not conscious of this; however, it is a part of me. Even as I write about my support of Hall's personal experience of medicalization, I am simultaneously betrothed, naively, to medicalization.<sup>1</sup>

Naivety is not an excuse. In fact, it is what angers me most about medicalization—this overreaching power that silences me. I am a nurse, a researcher, an educator, a human being who does not want to contribute to the damaging abuse caused by healthcare providers (and others) who demoralize, denigrate, and dehumanize individuals. I struggle with the supposed aspects of ethical nursing and medical care such as self-determination, autonomy, and patient-centered care. I see that these concepts are often disregarded in clinical practice and I wonder why the injustices are not challenged.

Hall relates quite clearly medicalization's effect on individuals.<sup>1</sup> Taking this dialogue further, how can self-awareness turn into action to not only stop participating, but to actively engage in changing it? Why don't we push for more research about the effects of this abuse on individuals, families, communities, ourselves? Why do we allow healthcare providers to treat human beings with such disrespect? Why do we as patients accept this behavior?

### *Fear as a force*

Fear is one reason individuals allow healthcare providers, including nurses, to treat them in a less than respectful manner. As Hall pointed out, patients risk losing access to their healthcare providers (if they are not compliant) because “trying to be partially in the healthcare system is like trying to be a little bit pregnant.”<sup>1 (p60)</sup> Research has shown that patients know that they risk being labeled difficult or noncompliant and face possible rejection from the healthcare system.<sup>6–9</sup> Personal experience and research show this to exist but healthcare providers often do not like to admit it. When I published an article in the American Journal of Nursing,<sup>10</sup> a letter to the editor following publication made this clear to me. One nurse denied that this phenomenon exists saying that she gives all patients the same care, regardless of their behavior, thoughts, beliefs, or level of compliance. While this is the ideal, it is unrealistic and an illusion to think that this always is the case. Previous research demonstrates how power and fear affect healthcare.

### *Research on power and fear*

A cursory review of the literature reveals that persons can be robbed of control and self-determination and that power has been used to keep patients under medical control. Taylor, Pickens, and Geden found that nurse practitioners used power to influence patient decision making about healthcare choices.<sup>11</sup> Nurses have been shown to exert power over patients through language consisting of demands, persuasion, controlling of the agenda, and terms of endearment.<sup>12</sup> Studies on nurse–patient communication have shown an inconsistency between nurses' self-perception of communication ability and what is observed.<sup>13</sup> The unethical social labeling of patients as “difficult” or “bad” has been shown to have negative effects on nurse–patient relationships and on the outcomes of care.<sup>7,8,14</sup> Patients try to manage their care environment in an effort to mitigate negative social labeling.<sup>9</sup>

Patients are aware that there is a medical agenda, that they are expected to follow that agenda, and that there are consequences for noncompliance. This awareness is shown in the words of this elderly hospitalized patient, “I have to do as I'm told. I'm 94 next week and I still have to do as I'm told.”<sup>12 (p80)</sup> What happens when patients do not “do as they are told?” Patients who disregard the medical agenda may be labeled difficult, bad, or simply rejected from the system altogether. It is understandable why patients want to avoid being labeled difficult since the quality of their care depends upon their positive relationships with their nurses and other healthcare providers.

## OUR VOICES: THEORETICAL EMERGENCE

The purpose of this discourse was to extend Hall's original essay through a discourse with our own personal stories of medicalization—<sup>2</sup> of us using our primary personal experiences with illness and <sup>1</sup> through professional work in the mental health field. We sought to respond to the ANS call for challenging, updating, or affirming previously published work. We also sought

theoretical emergence—clues to theory development grounded in shared personal and professional experiences. Emergence involves the coming forth out of obscurity, concealment, and confinement as well as implying something unexpectedly arising and demanding immediate attention.<sup>15</sup> The following points emerged in “our” voices going beyond the singularity of voices in each narrative:

We experienced medicalization diversely, depending upon our perspectives regarding the usefulness of medical diagnosis and treatment both prior to our critical illness experiences and during these experiences. There seems to be 4 distinct ways in which we experienced medicalization. Medicalization brought negative consequences that resulted in challenging and threatening the quality of life. Medicalization brought negative and positive consequences. The negative consequences were creation of fear, use of power to exert control over choices, and disregard for nonmedical model treatments and health-promoting activities. The positive consequences were treatments and surgical interventions that enhanced health, quality of life, and longevity. Medicalization brought positive consequences that included life-sustaining treatments, information about prognosis, and partnerships that enhanced health and well-being. Medicalization is a looming potential threat to personal well-being and to the quality of nursing and healthcare.

We experienced medicalization as a function of our expectations of healthcare providers regarding their role in our illness treatment and our relationships with them. A variety of expectations were articulated that were not each distinctive. Mona's expectation was that healthcare providers were expected to use the medical model and knowledge associated with medicalization and that they basically have noble intentions in doing so. It was expected that the shortcomings of this model and consequences of medicalization could be and were mediated by relationships with healthcare providers that educated and enlightened them about what was best for the individual. Richard had the expectation that some healthcare providers would likely be entrenched in the medical model and oblivious to the negative consequences of medicalization. He entered the relationships with providers believing that medicalization would be harmful and that alternatives to medicalization would be viewed skeptically. He thought that implementing his own course of treatment for success would mean limiting what he shared with healthcare providers. He thought healthcare providers might be recalcitrant to any attempts at mediation of their perspective, and might use power and authority to dismiss alternative views and demean proponents of these views, including patients. Hall 1 experienced healthcare provision in a similar way and advised that patients are best advised to raise their consciousness, secure personal power and information in the interest of their health and well-being, and to either challenge the healthcare providers or avoid sharing information that will be dismissed. Richard was the only one of the 3 participants in the discourse who had read Hall's work previously. He felt it was consistent with his experience as a patient and a nurse. Mona's perspectives were based on her experience as a nurse working with patients and she developed an attitude based on these experiences that nurses should align themselves with patients to advocate and support their wishes.

We experienced medicalization relative to how we responded and expected ourselves to respond to our diagnoses and treatments. Hall, Marti, and Richard had been diagnosed and treated for conditions that were viewed by the medical establishment as less life threatening with the right

course of treatment. There were several perspectives that guided our responses and expectations regarding diagnoses and treatment. One perspective was that it is important to know all the medical knowledge provided, including information associated with medicalization, to develop personal approaches to life, to health, and to the diagnosed illness or condition. Another perspective was that medical knowledge provided is flawed by inaccuracy and by its overemphasis on medicalization and should not be depended upon to make important life decisions. Furthermore, such knowledge has been used to exert unnecessary control and power over life decisions of patients and cannot be trusted. A final general perspective was that medical knowledge and the use of medicalization has some positive benefits, including valuable treatments and approaches, but should be used with some caution. In this perspective, medical knowledge should not be accepted without evaluation, should not be given the primary or singular role in treatment decisions, and should be used and integrated with nonmedical approaches that have value for the individual. Among this perspective there was wide variation in acknowledging and appreciating the potential role of fear both from within and in relation to medicalization.

Medicalization posed a variety of particular challenges for us that we viewed as relevant to caring for patients. Medicalization created conditions that challenged patients that varied from person to person, including inducement of fear related to treatment choices, limitations placed on patients' role in making decisions, unwillingness of providers to recognize the potentials of hope, spirituality, and alternative and complementary approaches, and the need to educate healthcare providers, particularly physicians, about such perspectives and approaches. Hall and the participants in this discourse had observed and/or experienced these challenges. These challenges were addressed by some form of action either individually or collectively. Individual actions included making self-determining and empowering choices about treatment and deciding to withhold information from healthcare providers deemed to result in negative consequences. Collective actions included encouraging dialogue among patients with similar medicalization experiences and promoting consciousness raising and reforms in healthcare.

Fear can be a prevailing force originating in a variety of sources related and not related to medicalization. Hall's 1 description of the fear she experienced related to recommendations for treatment, and the consequences of deciding a course of action not affiliated with medicalization was profound and encompassing. She described fears that were primarily imposed by the healthcare providers—fears associated with not taking their recommendations and constant reminders of the potential of dying. Marti did not experience a sense of fear associated with providers' recommendations. Richard did experience fear associated with such recommendations and Mona observed such fear in patients. Richard experienced fear from a variety of sources beyond the consequences of treatment. He made assumptions about the outcomes of treatment, particularly surgery, without reliable information. In fact, his fear took the form of avoidance of getting information. He became as afraid of the surgical intervention as of the life-threatening condition—a kind of fear that could not be reconciled. Richard also had a belief that his own thoughts would create consequences, both negative and positive, and had fears of his own conception of his condition. Some alternative and spiritual sources of assistance affirmed these fears, while others helped him resolve them or make sense of them and suggested strategies that led to a greater sense of peace and well-being. Thus, the nature of fear and its relationship to medicalization may be unique and contextual requiring deeper exploration.

Mobilizing personal power in the face of the dominance of medicalization was crucial to our well-being and health. Hall, Marti, and Richard shared the common feature of mobilizing personal power that assisted them in surviving their conditions and overcoming negative consequences of medicalization. Mona observed the importance of nurses providing opportunities for patients to exercise self-determination and personal power through the types of relationships formed. She advocates for turning self-awareness into action. There is a great emphasis across all these texts and in all the voices that gives testimony to the relevance of personal power in sustaining well-being and health. Further exploration of a variety of texts of those living with life-threatening conditions may illuminate and articulate the specific ways in which personal power makes a difference.

Nurses played a critical role in supporting freedoms to make choices not consistent with medicalization. All of us acknowledged and appreciated the critical role nurses play in supporting and sustaining patient-centered care in the midst of a treatment culture dominated by medical ideology and approaches. Those of us who were patients shared experiences that support the potential for healing that were described in the realms of hope, personal power, spirit, and approaches not grounded in medicalization. Each of the voices represented a call for awareness and action, albeit it varied, to address shortcomings inherent in the medicalization of human experiences. We all shared a concern for nurses participating in medicalization when it results in the repression of human freedom in living and dealing with life-threatening conditions.

Alternative and complementary healing modalities and the role of hope and spirit were crucial to enhancing our well-being. Alternative and complementary approaches were factors in enhancing and promoting health and well-being in both cancer and mitral valve malfunction. There seemed to be anecdotal evidence as well as research to support the efficacy and value of such approaches, often ignored by medical practitioners. Each person facing a healthcare problem or crisis was effective in dealing with their situation through mobilizing personal power, whether it was through direct confrontation, claiming the right to make treatment choices in spite of reluctance and challenge of practitioners, educating practitioners about nonmedicalized modalities, or developing a parallel nonmedicalized approach alongside a medicalized one.

We have not fully reconciled the value of medicalization and its obvious harmful consequences. The discourse highlighted tension between perceived value in the use of medicalization to assist individuals with life-threatening conditions and obvious harmful consequences described from personal experience. Medicalization brings with it a variety of useful and potentially life-saving interventions, such as the surgery used to repair Richard's mitral valve malfunction. At the same time, medicalization has been described as a force used to limit or deny possible useful interventions and spiritual perspectives not viewed as relevant by providers in the cases of Richard and Hall. This means that deeper and more explicit texts of personal experiences associated with medicalization may serve to more distinctly inform theoretical understandings of medicalization. We were left with the question, how can we create a life-enhancing coexistence for those of us who choose to blend approaches from both medicalization and alternative understandings of the human condition?

Our nursing backgrounds placed us in a position of having privileged knowledge about medicalization and alternatives to medicalization. Hall, Mona, and Richard are all academicians in the discipline of nursing, all have doctoral education, and we have all had clinical experiences as practicing nurses. Marti is an advanced practice nurse who has had extensive clinical experiences and is master's-prepared. We have had opportunities to study and explore critical issues associated with diagnoses and treatment of conditions. Our discourse has been shaped in obvious and subtle ways by this privileged position. The question the 3 authors of this article asked themselves is, How might medicalization be experienced by someone not in this kind of privileged position? It was certainly clear that our notions of what was valuable to patients were shaped by our education and practices in providing care to them. Given our obvious commitment to Hall's 1 position of advocating for the use of personal experience as a source for revealing the authentic meaning of medicalization, we advocate more extensive study of personal texts on the experiences of treatment as a means of informing emergent theories of medicalization.

## SUMMARY

Hall yearned for consciousness raising in nursing and for reform in healthcare that would overcome the subjugation of the human spirit and hope resulting from medicalization.<sup>1</sup> Whether this subjugation is intentional or not, our voices give attention to personal experiences that have been influenced by the medicalization of human conditions and to its impact on patients. Our voices also reveal the relevance of personal experience in deepening and broadening our understanding and appreciation of medicalization. We all share a concern for nurses participating in medicalization when it results in the repression of human freedom in living and dealing with life-threatening conditions.

What is most obvious for us is what lies beneath the oppression and distortion of medicalization. All of our accounts of medicalization, including Hall's,<sup>1</sup> reveal the potentials of the human spirit and possibilities of transformation. It is evident that medicalization of human conditions yields approaches that enhance health. It is simultaneously evident that medicalization has been used to reduce the human condition to controllable and manageable entities. Medicalization has been used for the purposes of a medical care system to extend its power and influence. Society is in need of an alternative to medicalization that acknowledges and embraces, rather than denies and subjugates, the potentialities of the human spirit. Nursing's theoretical, practical, empirical, experiential, aesthetic, and ethical groundings create the knowledge base for such an alternative. What must come forth out of concealment, confinement, and obscurity is an evolutionary manifestation of nursing. The questions that have emerged from this discourse invite us to connect our work to questions of the human spirit and the human potential for transformation—creating a field of theoretical knowing worthy of human inspiration.

## REFERENCES

1. Hall B. An essay on an authentic meaning of medicalization. *Adv Nurs Sci*. 2003;26(1):53–62.
2. Allan JD, Hall BA. Challenging the focus on technology: a critique of the medical model in a changing healthcare system. *Adv Nurs Sci*. 1988;10:22–34.
3. Rogers ME. Nursing science and the space age. *Nurs Sci Q*. 1992;5(1):27–34.
4. Cowling WR, Chinn PL, Hagedorn S. *The Nurse Manifesto*. 2000. Available at: <http://www.nursemanifest.com/manifesto.htm>. Accessed April 13, 2006.

5. Frankl VE. *Man's Search for Meaning: An Introduction to Logotherapy*. 3rd ed. New York: Simon and Schuster; 1984.
6. Breeze JA, Repper J. Struggling for control: the care experiences of “difficult” patients in mental health services. *J Adv Nurs*. 1998;28(6):1301–1311.
7. Carveth JA. Perceived patient deviance and avoidance by nurses. *Nurs Res*. 1995;44(3):173–178.
8. Finlay L. Good patients and bad patients: how occupational therapists view their patients/clients. *Br J Occup Ther*. 1997;60(10):440–446.
9. Shattell M. Nurse-Bait: Strategies hospitalized patients use to entice nurses within the context of the nurse-patient relationship. *Issues Ment Health Nurs*. 2005;26(2):205–223.
10. Shattell M. You catch more flies with honey: but patients shouldn't have to manipulate nurses to receive good care. *Am J Nurs*. 2005;105(2):13.
11. Taylor S, Pickens J, Geden E. Interactional styles of nurse practitioners and physicians regarding patient decision making. *Nurs Res*. 1989;38(1):50–55.
12. Hewiston A. Nurses' power in interactions with patients. *J Adv Nurs*. 1995;21:75–82.
13. Hewiston A. Power of language in a ward for the care of older people. *Nurs Times*. 1995;91(21):32–33.
14. Erlen JA, Jones M. The patient no one liked. *Orthop Nurs*. 1999;18(4):76–79.
15. Oxford University Press. *Oxford English Dictionary*. 2006. Available at <http://dictionary.oed.com/entrance.dtl>. Accessed April 13, 2006.