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Mein Körper sagt mir, er will nicht mehr tanzen. Krankheit als Signal und Chance

[My body tells me it doesn't want to dance anymore. Illness as signal and chance.]

Barbara Klose-Ullmann. Munich: Piper Verlag, 2003, 275 pages, € 19.90 hardcover.

Reviewed by Eva Brams, New York City

Barbara Klose-Ullmann's book, written in German, *Mein Körper sagt mir, er will nicht mehr tanzen. Krankheit als Signal und Chance*, grew partially out of her own experience with a potentially fatal illness, a brain tumor. Her diagnosis, her life-saving but also dangerous operation, her convalescence, and her successful return to an active life style brought about major changes in her outlook on illness and on life. When Klose-Ullmann then met a friend who had recently been diagnosed with multiple sclerosis, she decided to explore how others coped with illness and to write about her findings.

This book differs from others about illness in its scope and intent. It is a compendium of interviews with seriously ill people, from a variety of backgrounds. All chapters are succinct first-person accounts of their experiences and reliance on their own methods for dealing with illness. The interviews follow people from diagnosis through treatment to often difficult life changes. The range of illnesses described, and the differences among the interviewees, give readers a broad perspective. A bibliography at the end of the book lists other helpful health-related literature.

Although other authors include occasional excerpts of patients' accounts in their books to illustrate their psychological theories, (e.g., Kleinman, 1989; Siegel, 1990), these works usually don't follow anyone's story over time. There are also books that focus on one particular illness and its ramifications

Requests for reprints should be sent to Eva Brams, CSW
4 Washington Square Village, Apt. 17-I, New York, NY 10012-1910

(e.g., Kübler-Ross, 1987; Senelick, 1999), whereas Klose-Ullmann's book includes chapters on a variety of illnesses. Others focus on the physical/medical aspects of a serious illness (e.g., Dolin, 2002; Link, 2003; Ornish, 1995) but, in general, these books are written for physicians, whereas Klose-Ullmann's book is accessible to the lay reader. Rossi (1993) draws on psychology, neurobiology, medicine, information-processing theory, and hypnosis in his exploration of a variety of illnesses and of healing; but his book is rather technical. In still other books, the authors recount their own experiences with an illness and their ways of coping (e.g., Armstrong, 2000; Korda, 1997; Reeve, 1999).

In Klose-Ullmann's book, each interview shows a person who learned to cope well and, in most cases, succeeded in finding new pleasures in spite of, or even because of, life changes that were necessitated by an illness. Some of the people interviewed are still in their recovery phase; they are struggling to shape their new perspective. Others suffer from illnesses that cannot be cured or are certain to worsen. Remarkably, these people have particularly encouraging stories to tell.

Klose-Ullmann avoids exploring people's psychological histories beyond their own spontaneous revelations. She does, however, ask about the factors that might have precipitated the onset of an illness (e.g., stress at work or in a relationship; a person's need to excel). The author also addresses how illness affected a person's psychological state; how families, employers, and colleagues reacted to illness-related changes; and what type of psychological support was offered and used following a diagnosis.

Klose-Ullmann states clearly in her introduction and repeats in her conclusion that this book is meant to be neither a representative nor a scientific study. One might be tempted, when reading about the successful use of one method or another for coping with illness, to urge that method on relatives and friends. But the book makes clear that different people may need very different approaches when faced with a life-changing illness, and that they tend to find their own methods. One just needs to listen to them. Klose-Ullmann's key goal in this book is to be helpful: to give hope and identify the factors that people with severe illnesses find supportive.

Besides giving an account of her own illness and its consequences, Klose-Ullmann interviewed twelve women and six men who either experienced a serious illness or are still living with it. These subjects came from different backgrounds and range in age from 30 to 73. Their illnesses include benign tumors, cancer, heart disease, stroke, multiple sclerosis, and even an only recently recognized illness, chronic fatigue syndrome, among others. However, a major illness of our time, AIDS, is not represented. Several of the people interviewed suffer from more than one illness. Most of the illnesses described are of a physical nature, but some of the people interviewed suffered from psychosomatic illnesses, and most of them described periods of feeling depressed after being diagnosed and during later setbacks. While none of the subjects had a primary diagnosis of a psychiatric illness, the relationship between a person's health of mind and health of body is a theme explored in most of the interviews.

All subjects were offered a variety of aftercare programs, including rehabilitation through physical and occupational therapy, speech therapy, and psychotherapy. Most subjects were either successfully employed or saw promising employment opportunities before them when they became ill. But one woman, Susanne, was still in high school when she suffered her first stroke at age 15; she had to interrupt her education but returned to it later. By the time of her interview, Susanne had suffered a second, more severe stroke; yet she retained her positive outlook on life. A speech therapist, Horst, had suffered a painful skin disease since age 11 but was not correctly diagnosed until he was in college. The people interviewed were at various stages of recovery and had received very different prognoses.

Although Klose-Ullmann made an effort to recruit a variety of people for her research, there are limitations to the method she used to find her subjects. She asked friends, their friends and their acquaintances, and people at conferences and at all kinds of social gatherings for the names of potential volunteers for her interviews. Thus, all interviewees either were previously known to the author or had a closer connection to her than randomly selected people would have had. Most of them were financially secure, and all of them were articulate and resourceful. Twice as many women volunteered as did men.

Klose-Ullmann's questions are brief and unobtrusive, so that we are not distracted from the narratives of the interviewees. The questions are similar for each participant and differ mostly in following

the particulars of someone's story, or in allowing a person to elaborate. The interviews include questions about people's medical, psychological, and professional experiences before, during and after their illnesses. Subjects' relationships with important other people in their lives are also explored. The author includes sufficient medical details for us to form an impression of an interviewee's personal circumstances, health problems, and the treatment received without overwhelming us with medical jargon.

Klose-Ullmann acknowledges that some people may have answered questions in ways designed to please her, i.e., to help her to confirm her hypothesis that illness can be enriching. However, in some instances, she designed a question in such a way that she increased the likelihood of receiving a desired answer. For example, the question, "Regarding quality of life: what did you lose, what did you gain?" (p. 194) suggests that illness brings both loss and gain, which may not be true for all people. Moreover, discussing her outlook on her own illness with some of the interviewees might have given them a good idea of what she hoped to hear. Nevertheless, the answers Klose-Ullmann elicits have the ring of truth and are often so specific that they could not be invoked just to please the author.

A recurring question in the book is whether people experienced their illness as a signal (warning) or as a chance to reshape their lives and increase their personal fulfillment. A surprising number of people reported that their lives actually improved, even if the illness was a heavy price to pay for what they gained.

Klose-Ullmann succeeds in eliciting highly personal statements from those she interviews without ever pressing for an answer that a person might not feel comfortable giving. The answers she receives show the originality and sincerity of her subjects, often surprising the reader. Her sensitivity is reassuring to the reader, and it might serve as instruction for medical personnel.

The book's emphasis is on the factors that helped people cope with their medical experiences and their life changes. These factors can be concrete, such as getting regular physical therapy or receiving a

wheelchair (p. 226), or they can be less tangible, such as sincere concern by someone on the medical staff (pp. 224-225), or feeling the healing powers of a walk in the woods (p. 39).

One woman who underwent a mastectomy (p. 169) devised her own mental strategies: when she was told that she would receive chemotherapy and radiation after her surgery, she felt that she was doubly lucky; she thought of these treatments as two chances to attack any cancer cells that might remain. The metaphor she used for chemotherapy was a healing potion that she welcomed drop by drop. Although she initially became ill after chemotherapy sessions, she eventually taught herself to manage treatment without becoming nauseous. She also described how she instructed her soul at bedtime to go to work at night and to heal areas of her body that troubled her. This woman and others were inspired by a book by Simonton, Mathews-Simonton, and Creighton (1992), which instructs people in the use of cognitive methods to cooperate more effectively with their physicians in furthering the healing process.

A 53-year-old single mother of two daughters, whose husband had been a philanderer and who left her on the day of her mother's funeral, became furious when she was diagnosed with breast cancer. She felt that suffering was heaped unfairly upon her. But after each setback, she found new hope and new strength. To calm her mind and avoid succumbing to her illness, she took many walks in the woods and also listened to the J. S. Bach motets, "Fürchte Dich Nicht" (p. 49).

Other helpful factors mentioned by people included being well informed by their physicians about their illness and about medical procedures. But one man preferred to trust that his physician would know how to treat him and that he would not trouble him with medical details (p. 216). This same man passed up the opportunity to go to a rehabilitation sanatorium after his release from the hospital. He said, however, that he attended some seminars on personality development and read such books as Watzlawick's (1983) *The Situation is Hopeless, But Not Serious*, which taught him to use cognitive strategies to motivate himself and to maintain a positive attitude. He stated that his prompt return to work helped him to regain his focus on life and to avoid talk of illness. However, others interviewed reported greatly benefiting from the care they received during their stays in sanatoriums.

One woman said she was “rescued” from her state as an invalid by her husband’s and children’s acting “as if nothing had happened.” She stated that she valued her husband’s preoccupation with his work and her children’s demands on her (p. 199). She believed that she would not have tested herself sufficiently without the ongoing challenges of running a household. In contrast, many other respondents found support, understanding, and indulgence from professionals, and family and friends, very helpful. Generally, people found a holistic approach to health care beneficial. Several people were helped by writing (e.g., p. 232) and speaking (e.g., p. 74) about their experiences with illness.

Naturally, the interviews also brought to light some factors that were counterproductive. It is shocking how many people reported having been repeatedly misdiagnosed. For example, a 49-year-old woman, Marlies, who suffered from serious urination problems, was initially told by her female gynecologist that many women her age suffered from such problems. The gynecologist minimized all of Marlies’s symptoms as normal signs of aging and prescribed hormone therapy. Marlies’s problems worsened in spite of repeated medical exams and changes in hormone therapy. Two years after her initial complaints, Marlies experienced a painful episode of being completely unable to urinate for 16 hours. This incident prompted her to seek out other physicians. She spoke of an “odyssey” of visits to “urologists, gynecologists, radiologists, and neurologists” (p. 52), all of whom failed to identify her illness while her symptoms steadily worsened. One urologist told her that her bladder looked 20 years older than she was, and that it resembled that of an old prostate patient. Marlies even underwent surgery to widen her urinary tract, which further worsened her condition (pp. 53-54).

Finally, she consulted a well-known radiologist in another city. This male physician called Marlies’s medical experience a scandal. His tests revealed that a tumor grew around her urinary tract, strangling it and making urination nearly impossible. Through further tests and eventual extensive and life-threatening surgery, Marlies learned that she had eight malignant tumors, and that suture materials from the earlier surgery to widen her uterine tract had become interwoven in tumors and in spongy blood accumulations (p. 55). During her recovery, Marlies had to cope with great physical pain and also with the disappointment of disfigurement from the surgery. Although this part of her story is frightening, Marlies’s subsequent courage and her resumption of a full life are very encouraging.

Horst, a speech therapist mentioned above, suffered from hyperkeratosis, a hereditary skin disease that affected his feet from the time he was 11 years old. He received one wrong diagnosis after another and equally many ineffectual medications (pp. 125-126). For years, he experienced chronic pain and walked with crutches. His pain eventually prevented him from sleeping and from concentrating on anything other than his illness. When he finally received the correct diagnosis and appropriate medication, he was 27 years old. At the time of his interview, Horst expressed acceptance of his illness and viewed the side effects of his medication as tolerable inconveniences. His focus, however, was on his excitement about his work and on the professional goals he set for himself.

Besides misdiagnosis, insensitivity and even rudeness by medical staff was the next most vexing factor in patient treatment. This problem seemed to happen to women more often than to men. Susanne, the teenage girl mentioned above, who had spent her childhood caring for her alcoholic mother and who never touched alcohol herself, was ignored by physicians in the emergency room for hours. The physician and nurses loudly suggested that she was just drunk when, in fact, she had suffered a severe stroke that left her alert but without movement and speech. The physician then proceeded to taunt the helpless girl. After she was finally accurately diagnosed and admitted to the hospital, "10 to 15 physicians" stood around her bed and discussed her case. "What a shame," they said, "this young girl, just 15 years old, will never be able to speak or walk again," not realizing that she heard and understood them (pp. 223-224). She did speak and walk again and, even though she had suffered a second stroke by the time of her interview, she provided one of the most touching stories in the book.

As for finding a benefit in an illness, one woman put into words what other people only hinted at. She referred to a television program about organizational changes. The message was that, at first, people are shocked and refuse the changes. But when they realize that they have no choice, they try to cooperate, and in the end they fully accept the changes (p. 206). This is in agreement with the stages toward acceptance of approaching death that Kübler-Ross (1969) describes. Once people accept what they cannot avoid, they sometimes even find something positive about the new situation. Horst, who suffered from hyperkeratosis, put it well when he said, "There were times when I was very ashamed about

my peculiar gait, my sick feet. One is constantly reminded of it. One can despair over it, or one can make it one's challenge. Then it can at least become productive" (p. 129).

Some of the gains that people mentioned were that they had more time to pursue activities they loved, that they became more compassionate and introspective, that they realized that others cared about them independently of their achievements, and that they were able to make new friends. Some stated without reservation that their illness enriched their lives; but others confessed that if they had understood the consequences of their life style earlier, they would have changed their habits rather than to live with the limitations that their illness now imposed.

While many of the stories in Klose-Ullmann's book will be of universal appeal, there are aspects that relate very specifically to the German health-care system, which offers significantly more generous benefits than do health insurance plans in the United States and other countries. Very few countries offer rehabilitative-sanatorium stays that last for weeks, months, or even a year and that are paid for by the government or by private health insurance companies. In Germany, these sanatorium stays include physical therapy, massages, speech therapy, psychotherapy, group discussions, classes in a variety of leisure activities such as yoga, Chi Gong, and crafts—whatever a person needs or desires. They also include swimming pools and walks in the countryside. But even Germany's health-care services are not equally available to everyone. A woman who suffered from bone marrow cancer was able to pay for expensive treatments that were not included in her benefits package. Remembering others who were less financially secure, she said, "The reality is, if you are poor, you must die sooner. I find that depressing" (p. 144).

In the United States, even people with private insurance, good income, and savings cannot expect the kind of health care that Germans routinely receive. US citizens are lucky if their aftercare benefits cover Visiting Nurse Service and Meals-On-Wheels. Services are strictly limited and largely unrelated to a person's needs (they depend on a person's type of insurance). For example, a 41-year-old city administrator, who was my client in psychotherapy, had two heart attacks, multiple strokes, and serious complications from several surgeries. He was discharged from a three-month hospital stay to go home.

(A sanatorium stay is generally not included in health plans in the United States.) Fortunately, his mother was able to care for him initially.

A year later, he still had not recovered his ability to speak clearly, and he still felt weak and vulnerable, but he had to return to work, as he had used up all his savings. At work he was repeatedly told that people could not understand him. His speech therapy had been halted after his 20-session limit, and he was told that he could not get more sessions. Every aspect of his care depended on the limited allowances of his insurance company. He had to work unpaid overtime to make up for his handicaps. Moreover, he was unable to take vacation, as all his vacation time far into the future had been used up by his illness and recovery. One day he said, "I think they are trying to kill me."

In *Mein Körper sagt mir, er will nicht mehr tanzen*, there are a few interviews with people who spoke about financial concerns. Single mothers who were the sole providers for their children had the most difficult experience (e.g., pp. 30-32, 65, 181). But most subjects stated that they enjoyed working again and had good health insurance, or that they had savings, good pension plans, or sufficient government assistance. For example, Horst, whose parents died both during his childhood, found himself at one point at the end of his money and depressed about his painful skin disease (pp. 130-131). He then received disability status, which entitled him to financial and educational assistance. By the time of the interview, he was employed and excited about his career. Few countries care for people with illnesses to such an extent.

This is not to minimize the contributions of any of the people who volunteered to discuss their stories. Every interview offers new insights and perspectives. Although no one approach to living with or recovering from an illness can fit everyone, most readers will find something in this book that will remain with them. The courage and the life-affirming attitude of all the men and women who told their stories are inspiring.

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