KEY WORDS FOR MEDICAH HUMANITIES

ARTETERAPIA (ART THERAPY): Art therapy is a form of expressive therapy that uses the creative process of making art to improve a person's physical, mental, and emotional well-being. The creative process involved in expressing one's self artistically can help people to resolve issues as well as develop and manage their behaviors and feelings, reduce stress, and improve self-esteem and awareness. Art therapy can achieve different things for different people. It can be used for counseling by therapists, healing, treatment, rehabilitation, psychotherapy, and in the broad sense of the term, it can be used to massage one's inner-self in a way that may provide the individual with a deeper understanding of him or herself.

Art therapists are trained to pick up on nonverbal symbols and metaphors that are often expressed through art and the creative process, concepts that are usually difficult to express with words. It is through this process that the individual really begins to see the effects of art therapy and the discoveries that can be made. (http://www.arttherapyblog.com/what-is-art-therapy/#arttherapist)

AUTOPATHOGRAPHY: "Bodily dysfunction may stimulate what I call autopathography -Autobiographical narrative of illness or disability- by heightening one's awareness of one's mortality, threatening one's sense of identity, and disrupting the apparent plot of one's life." (Couser, Thomas. *Recovering Bodies: Illness, Disability, and Life Writing.* The University of Wisconsin Press, 1997: 5)

--- The term autopathography, is useful to distinguish first-person illness narratives from those told by another, in the third person. Its focus is typically not on the medical condition or details of treatment. Rather, it critiques social constructions of the disabled body and incorporates a counternarrative of survival and empowerment that reclaims the individual's or a loved one's body from the social stigmatization and the impersonalization of medical discourse.

AUTOTHANATOGRAPHY. This term has recently been applied to autobiographical texts that confront illness and death by performing a life at a limit of its own, or another's, undoing. Nancy K. Miller suggests that "autobiography—identity through alterity—is also writing against death twice: the other's and one's own." For Miller, in a sense "every autobiography, we might say, is also an autothanatography," since the prospect of nonexistence looms inescapably ("Representing Others," 12). Susanna Egan, in an extended treatment of autothanatography, focuses on how the attention of recent life narrators to issues of terminal illness "intensifies the rendition of lived experience, the immediacy of crisis, and the revealing processes of self-understanding" in the process of dying (*Mirror Talk*, 200). AIDS-related autothanatography, Egan notes, confronts death head on: "Death writing becomes preeminently life writing, and a bid to take charge of how that life writing is read" (207). It is "part of a complex claiming of agency" that attempts to connect the organic to the symbolic (208). At the zero-degree of both life and autobiography, with the death of the writing, or visual, or filmic life narrator, "the subject becomes an object entirely exposed to being read, entirely dependent on its reader for constructions of meaning" (212). Egan suggests that even in monologic

autothanatographies, such as Audre Lorde's *The Cancer Journals* and a burst of light, the text is dialogic, the voice polyphonic, in integrating the anticipation of death into living (215). Making a record of living in a text that outlives the life, autothanatographies intensively "focus on illness, pain, and imminent death as crucial to the processes of that life" (224) (From: Smith and Watson, *Reading Autobiography*. U of Minnesota P, 2003: 188)

CASE STUDY/HISTORY: This term designates a life narrative that is gathered into a dossier in order to make a diagnosis and identification of a disease or disorder. This mode of life-reporting is often associated with Freud's extended analyses of the cases of various patients with symptoms such as hysteria and gender-identity disorder. The treatment begins with the patient's producing of a story of unhappiness and illness. The unsatisfactory nature of this first narrative usually lets the analyst "see his way about the case" (66) in gaps, hesitations, inconclusiveness, and changes in dates, times, and places. That is, the narrator/patient presents clues to another story she is unable to tell. Freud's emphasis is on making, with the patient, a new and coherent narrative that, in giving the patient possession of a past life, enables her to own her own story. Another sense of the case study is discussed in *Landscape for a Good Woman* by Carolyn Kay Steedman, who critiques its ability to embed gendered social history in the story of rural working-class British mothers (From: Smith and Watson, *Reading Autobiography*. U of Minnesota P, 2003: 130–31).

CATHARSIS: (from Greek κάθαρσις, katharsis, meaning "purification" or "cleansing" or "clarification") refers to the purification and purgation of emotions—particularly pity and fear—through art or any extreme change in emotion that results in renewal and restoration. It is a metaphor originally used by Aristotle in the *Poetics*, comparing the effects of tragedy on the mind of a spectator to the effect of catharsis on the body.

A catharsis is an emotional release. According to psychoanalytic theory, this emotional release is linked to a need to relieve unconscious conflicts. For example, experiencing stress over a work-related situation may cause feelings of frustration and tension. Rather than vent these feelings inappropriately, the individual may instead release these feelings in another way, such as through physical activity or another stress relieving activity.

The Meaning of Catharsis

The term is used in therapy as well as in literature. The hero of a novel might experience an emotional catharsis that leads to some sort of restoration or renewal. The purpose of catharsis is to bring about some form of positive change in the individual's life. Catharsis involves both a powerful emotional component in which strong feelings are felt and expressed, as well as a cognitive component in which the individual gains new insights.

Catharsis in Psychoanalysis

The term has been in use since the time of the Ancient Greeks, but it was Sigmund Freud's colleague Josef Breuer who was the first to use the term to describe a therapeutic technique. Breuer developed what he referred to as a "cathartic" treatment for hysteria. His treatment involved having patients recall traumatic experiences while under hypnosis. By consciously expressing emotions that had been long repressed, Breuer found that his patients experienced relief from their symptoms. Freud also believed that catharsis could

play an important role in relieving symptoms of distress. According to Freud's psychoanalytic theory, the human mind is composed of three key elements: the conscious, the preconscious, and the unconscious. The conscious mind contains all of the things we are aware. The preconscious contains things that we might not be immediately aware of but that we can draw into awareness with some effort or prompting. Finally, the unconscious mind is the part of the mind containing the huge reservoir of thoughts, feelings, and memories that are outside of awareness.

The unconscious mind played a critical role in Freud's theory. While the contents of the unconscious were out of awareness, he still believed that they continued to exert an influence on behavior and functioning. By using psychotherapeutic tools such as dream interpretation and free association, Freud believed that these unconscious feelings and memories could be brought to light. In their book *Studies on Hysteria*, Freud and Breuer defined catharsis as "the process of reducing or eliminating a complex by recalling it to conscious awareness and allowing it to be expressed." Catharsis still plays a role today in Freudian psychoanalysis.

The American Psychological Association defines catharsis as "the discharge of effects connected to traumatic events that had previously been repressed by bringing these events back into consciousness and re-experiencing them." Catharsis in Everyday Language

The term catharsis has also found a place in everyday language, often used to describe moments of insight or the experience of finding closure. An individual going through a divorce might describe experiencing a cathartic moment that helps bring them a sense of peace and helps that person move past the bad relationship.

People also describe experiencing catharsis after experiencing some sort of traumatic or stressful event such as a health crisis, job loss, accident, or the death of a loved one. While used somewhat differently than it is traditionally employed in psychoanalysis, the term is still often used to describe an emotional moment that leads to positive change in the person's life. (From https://www.verywellmind.com/what-is-catharsis-2794968)

DIAGNOSTIC RELATED GROUPS (DRGs): DRGs are detailed statements of what medical treatments some third party insurer will pay for, based on the diagnosis at the time of hospital admission. The DRG is a narrative that sets in place details of the experience of the hospitalization that will follow. The DRG reduces the general unifying view to bureaucratic proceduralism. DRGs do epitomize the dehumanizing aspect of "becoming a patient." (Arthur Frank, *The Wounded Storyteller*, 64). See: https://en.wikipedia.org/wiki/Diagnosis-related_group

DISEASE vs ILLNESS: (From "The cancer memoir: in search of a writing cure?" by Anne Karpf, in Burke, *The Topic of Cancer: New Perspectives on the Emotional Experience of Cancer*)

Kleinman crucially distinguishes between the concepts of **disease** and **illness** (Kleinman, 1988). **Disease** is a *biomedical category* and diagnostic entity, a physiological disorder for which technical solutions are sought. In this paradigm the patient becomes the case-history, the object of professional inquiry. In the *biopsychosocial model*, by contrast, **illness** is part of a symbolic network that links the body, the self, and society. Kleinman, a psychiatrist and anthropologist, argues that medical training has blinded doctors to the meaning of illness: he wants to restore "the experiential realm of suffering"

(Kleinman, 1988, p. 267) to the physician's gaze, calling for them to attend to patients' own narratives. As the American memoirist Anatole Broyard asked rhetorically, "How can a doctor presume to cure a patient if he knows nothing about his soul, his personality, his character disorder?" (Broyard, 1992, pp. 23–24).

EMPATHY: **(**https://greatergood.berkeley.edu/topic/empathy/definition) The term "empathy" is used to describe a wide range of experiences. Emotion researchers generally define empathy as the ability to sense other people's emotions, coupled with the ability to imagine what someone else might be thinking or feeling.

Goleman (greatergood.berkeley.edu/article/item/hot_to_help) differentiates between three types of empathy:

1. The first form is "***cognitive empathy***," simply knowing how the other person feels and what they might be thinking. Sometimes called *perspective-taking*, this kind of empathy can help in, say, a negotiation or in motivating people. A study at the University of Birmingham found, for example, that managers who are good at perspective-taking were able to move workers to give their best efforts. Studies suggest that people with autism spectrum disorders have a hard time empathizing. But cognitive empathy alone is not enough. We also need what Ekman calls
2. "***emotional empathy***"—when you physically feel what other people feel, as though their emotions were contagious. This emotional contagion depends in large part on cells in the brain called mirror neurons, which fire when we sense another's emotional state, creating an echo of that state inside our own minds. Emotional empathy attunes us to another person's inner emotional world, a plus for a wide range of professions, from sales to nursing—not to mention for any parent or lover.

   But emotional empathy has a downside, too, especially for first responders. In a state of emotional empathy, people sometimes lack the ability to manage their own distressing emotions, which can lead to paralysis and psychological exhaustion. Medical professionals often inoculate themselves against this kind of burnout by developing a sense of detachment from their patients. Cultivated detachment in rescue, medical, and social workers can actually help the victims of disaster.
3. "***Compassionate empathy***." With this kind of empathy we not only understand a person's predicament and feel with them, but are spontaneously moved to help, if needed. Compassionate empathy was the vital ingredient missing from the top-level response to Hurricane Katrina—and in responses to many other disasters around the world, including the slow-burning disaster of global warming. Ekman calls compassionate empathy a skill, the acquired knowledge "that we're all connected." This can lead to outbursts of what he calls "constructive anger." In other words, reacting negatively to injustice or suffering can motivate us to work with others to make the world a better place. Just as empathy has its downsides, negative emotions like anger can have upsides. Staying cool in a crisis might bring some benefits. But sometimes we must let ourselves get hot in order to help.

Empathy seems to have deep roots in our brains and bodies, and in our evolutionary history. Elementary forms of empathy have been observed in our primate relatives, in dogs, and even in rats. Empathy has been associated with two different pathways in the brain, and scientists have speculated that some aspects of empathy can

be traced to mirror neurons, cells in the brain that fire when we observe someone else perform an action in much the same way that they would fire if we performed that action ourselves. Research has also uncovered evidence of a genetic basis to empathy, though studies suggest that people can enhance (or restrict) their natural empathic abilities.

Having empathy doesn't necessarily mean we'll want to help someone in need, though it's often a vital first step toward compassionate action.

For more: Read Frans de Waal's essay on "The Evolution of Empathy" and Daniel Goleman's overview of different forms of empathy, drawing on the work of Paul Ekman.

> We are so used to empathy that we take it for granted, yet it is essential to human society as we know it. Our morality depends on it: How could anyone be expected to follow the golden rule without the capacity to mentally trade places with a fellow human being? It is logical to assume that this capacity came first, giving rise to the golden rule itself. The act of perspective-taking is summed up by one of the most enduring definitions of empathy that we have, formulated by Adam Smith as "changing places in fancy with the sufferer." (Waal)

NARRATIVE MEDICINE: **(From Marini's *Narrative Medicine*)** Narrative Medicine refers to the set of stories on symptoms and perceptions narrated by the persons most directly and closely involved—hence most often the patients themselves, but also loved ones and carers—which invite/give space to the description of feelings, emotions, mindset. The goal of narrative medicine from its start has been to improve healthcare. As Greenhalgh states, Narrative Based Medicine can be defined:

> "Narrative medicine is what occurs between the health provider and the patient: from the collection of information of events before the occurrence of the disease, how the disease showed up, with attention to physical, psychological, social and ontological features (Greenhalgh 1999).

Narrative Medicine (NM) is often studied in correlation with ***EVIDENCE-BASED MEDICINE*** *(EBM)*. A cornerstone of medicine and of today's clinical research, the concept of Evidence-Based Medicine (EBM) was first introduced in the 1970s by the epidemiologist David Sackett and his pioneering approach to introducing standardization into clinical research methodology. His studies evidenced the many flaws in research and addressed ways to reduce bias in clinical research by standardizing the design, conduct, and report of randomized clinical trials in scientific literature. Likewise, Sackett was just as methodical in analysing health conditions and disorders, focusing on their cause, diagnosis, prognosis, clinical prediction, prevention, treatment, and amelioration in the prospective of defining a balance between quality and cost-effectiveness of health services. As EBM had finally set a shift from the subjective "opinion" of the carer to a more reliable and organized way of performing research, it gained growing acceptance and has become in just a few decades the dominant paradigm of science and medicine—and not least the main philosophy at the basis of the teaching system in scientific academy, medicine, nursing, and biomedical sciences. EBM has spread throughout North America and Europe, in a globalizing trend, such to be acknowledged by the World Health Organization as the *primum movens* of the evolution of clinical science.

However, Sackett's definition—the care of individual patients—leads us to approach the paramount issue of patients as ***individuals***. We must notice here that the term individual relates to a singularity, whereas patients refer to a plural entity. Such nuance per se is an extremely relevant issue. Yet it appears to have been neglected by

researchers involved in designing and performing clinical trials, who have remained oriented to addressing the exclusively populations and patient subgroups, where individuality is sacrificed in favour of the broader picture and generalization of results.

However, because of its leading role as a decision-making tool, EBM inevitably exerts strong influences well beyond the medical field, representing a strong economical driver in a number of areas of industry, such as pharmaceutical, health care, insurance, and others.

Currently, **NARRATIVE MEDICINE** is taught and applied in many centers worldwide, but the two main schools of thought are London's King's College Center for Humanities for Health and the New York Columbia University Medical Center, Program in Narrative Medicine. Brian Hurwitz and Tricia Greenhalgh (1999) of King's College in London were the first to describe the benefits of this discipline in their "*Why study Narrative*", referring to health-care practice:

> "Narrative provides meaning, context, perspective for the patient's predicament. It defines how, why, and what way he or she is ill. It offers, in short, a possibility of understanding which cannot be arrived at by any other means.

• In *the* ***diagnostic encounter,*** narratives:
- Are the phenomenal form in which patients experience ill health
- Encourage empathy and promote understanding between clinician and patient
- Allow for the construction of meaning
- May supply useful analytical clues and categories

• In the ***therapeutic process***, narratives:
- Encourage a holistic approach to management
- Are intrinsically therapeutic or palliative
- May suggest or precipitate additional therapeutic options

• In the ***education*** *of patients* and health professionals, narratives:
- Are often memorable
- Are grounded on experience
- Encourage reflection

• In ***research,*** narratives:
- Help to set a patient-centered agenda
- May challenge received wisdom
- May generate new hypotheses

In Rita Charon's words, "Literary theory, narratology, continental philosophies, aesthetic theory, and cultural studies provide the intellectual foundations of narrative medicine." (Charon, *The Principles and Practice of Narrative Medicine*: 1)

Medical care is related to health care, and that narrative medicine might belong to all health-care providers (nurses, social workers, psychological professionals) who are already prepared to think and act through narratives. Broadening this view, Narrative Medicine can involve also decision-makers in Health Care, and active citizenship associations, patient associations, and carers (Marini and Arreghini 2012). Narrative medicine is *democratic* (Marini 2013): it is able to connect patients and health-care

providers and link evidence-based medicine and medicine based on narrative, as well as clinical sciences and human science.

Narrative medicine as well as **medical humanities** mainly developed in the late twentieth and twenty-first century as a tool to give voice back to patients, fragile people, and persons who had no right to speak and claim how they lived their disease. A cult book for narrative applied to medicine is *The Wounded Story Teller: Body, Illness, and Ethics*, by Arthur Frank, a sociologist who teaches at Calgary University and who had a direct experience facing a cancer (Frank 1995). Frank states: illness narratives can be appointed to three major categories: restitution, chaos, and quest.

> "**Restitution** stories attempt to outdistance mortality by rendering illness transitory**. Chaos** stories are sucked into the undertow of illness and the disasters that attend it. **Quest** stories meet suffering head on: they accept illness and seek to use it. Illness is the chance for turning a journey into a quest".
>
> ("Las historias de **restitución** intentan superar la mortalidad haciendo que la enfermedad sea transitoria. Las historias de **caos** se centran en el curso de la enfermedad y los desastres que la acompañan. Las historias **de búsqueda** se enfrentan al sufrimiento: aceptan la enfermedad y buscan utilizarla. La enfermedad es la oportunidad de convertir un viaje en una búsqueda".)

PANDEMIA vs EPIDEMIA: Según la Organización Mundial de la Salud (OMS), se llama **pandemia** a la propagación mundial de una nueva enfermedad. Por ejemplo, se produce una pandemia en el momento en que aparece un nuevo virus de la gripe y se extiende por el mundo porque casi nadie tiene defensas frente a él. La mayor parte de las pandemias han sido causadas por virus gripales que afectan a los animales. Seguro que recuerdas la famosa gripe aviar. Hoy: CORONAVIRUS

Según la RAE, una **epidemia** es una enfermedad que se propaga durante algún tiempo por un país, afectando simultáneamente a un gran número de personas.

Diferencia entre pandemia y epidemia: la diferencia entre pandemia y epidemia radica en dos aspectos:

- La expansión desde el punto de vista geográfico de la enfermedad.
- El rápido aumento de los casos de personas afectadas por la enfermedad.

En una **pandemia** ambos aspectos tienen mayores proporciones que en una epidemia. El nivel de emergencia sanitaria que producen una epidemia y una pandemia depende de:

- El modo en que se propaga la enfermedad.
- La facilidad de la propagación.
- La posibilidad de contagio de las personas afectadas a las sanas.
- La relación entre las personas que están en peligro de contagio y las personas inmunes (por haber sido vacunadas, por ejemplo).

Además de las pandemias y de las epidemias, podemos hablar también de **endemias**. Según la definición de la RAE, una endemia es una enfermedad que reina habitualmente en épocas fijas en un país o comarca. Por lo tanto, se trata de casos de enfermedades

normales que afectan con frecuencia a un país o zona según la estación del año. Aunque la enfermedad afecta a muchas personas, en general no se trata de casos graves.

Cómo se detectan una epidemia o una pandemia
Actualmente la existencia de las epidemias o de las pandemias se puede detectar analizando las incidencias en una determinada zona durante un plazo de tiempo. Lo aconsejable es valorar los datos semanalmente o incluso diariamente en los casos de una rápida propagación y, sobre todo, trabajar en la prevención.

PATHOGRAPHY: (From Hunsaker, Anne "Pathography: patient narratives of illness") In ever greater numbers, people are writing autobiographical accounts of their experience of illness and treatment, narratives that are often called **pathographies** or **autopathographies**. Increasingly patients are turning to these narratives for anecdotal information about particular illnesses and their treatments, conventional and alternative. Hence the remarkable popularity of such books, many of them bestsellers. ***Pathographies*** not only articulate the hopes, fears, and anxieties so common to sickness, but they also serve as guidebooks to the medical experience itself, shaping a reader's expectations about the course of an illness and its treatment. *Pathographies* are a veritable gold mine of patient attitudes and assumptions regarding all aspects of illness. These narratives can be especially useful to physicians at a time when they are given less and less time to get to know their patients but are still expected to be aware of their patients' wishes, needs, and fears.

Pathographies embody the biopsychosocial model (See Disease/Illness, above); in them meaning—the meaning that the patient attributes to his symptoms and disease—is paramount. In the pathography-memoir the patient constructs his own narrative, which roams far beyond the medical encounter—indeed the medical encounter itself is scrutinized by the memoirist. Here subjective experience is not some "soft", devalued aspect of psychosocial concern in contrast to the "hard", scientific management of symptoms (Kleinman, 1988): disease becomes meaning and subjective experience. So the cancer memoir, for example, is less about cancer per se, and more about "what it feels like to be me with cancer". In restoring the patient's eye-view, pathographies also explicitly contrast it with the medical gaze.

Case reports are generally about a biomedical condition and its treatment; **pathographies,** on the other hand, concern illness and treatment as it is understood *by the ill person*. They differ in subject and in composition. The medical report is usually made up of impersonal statements by medical caregivers about symptoms, test results, and response to treatment. A pathography is an extended single-author narrative, situating illness and treatment within the author's life and linking them with the meaning of that life. Pathographies provide the story of illness from the perspective of the individual patient.

What value is it for physicians to read a single book narrating a single individual's illness experience? Are these books generalizable in any way? The answer is **yes.** One can categorize a pathography by the disease that is its subject, by dominant myths, attitudes, and assumptions, and by the author's intent in writing the book.

The common denominator of all pathographies, whatever the ostensible motives of their authors, is that the act of writing in some way seems to facilitate recovery: the healing of the whole person. For most of us, really serious illness is a painful, disorienting,

and isolating experience. It is a trauma, an insult not only to the body but also to the self. As Robert J. Lifton has shown, coming to terms with a traumatic experience often involves the attempt to project it outwards by talking or writing about it. Writing about an illness experience is a kind of psychic rebuilding that involves finding patterns, imposing order, and, for many, discovering meaning. Pathography, then, is not only a description of how awful it is to be seriously ill, but also a testimony to the capacity to transform that experience in ways that heal.

For physicians, pathographies can provide a unique "window" into the experience of their patients, often revealing aspects of patient experience that remain unarticulated in the medical encounter. These books can be medically useful for a number of reasons:

- They embody the patient's point of view on a variety of aspects of a medical experience.
- They offer a longitudinal view of illness as it is experienced before and after the patient encounters the physician. They embody the patient's point of view on a variety of aspects of a medical experience.
- They describe common issues in medical encounters that are often problematic, demonstrating both helpful and harmful ways in which a physician can deliver bad news; providing concrete examples of physicians who express (or fail to express) *empathy;* illustrating the patient's dilemma when confronted with conflicting advice from different medical experts.
- They provide information about alternative medical treatments from the perspectives of the patients who use such treatments.
- They reveal cultural attitudes and assumptions about illness, treatment, and recovery (the idea that illness is a battle or a journey, for example), showing how these can help (or fail to help) patients to better deal with their medical situations.

Types of pathography

Four different groups of pathographies emerge when one analyzes them according to authorial intent.

1) The first might be called "**didactic pathographies**." These narratives are motivated by the explicit wish to help others. Often they blend practical information with a personal account of the experience of illness and treatment. Descriptions of *breast cancer* experience, for example, have enabled women to become aware of therapeutic alternatives-both within and outside conventional medical practice. Other pathographies concern culturally problematic issues, such as assisted death, HIV discrimination, or the use of alternative medicine, and are based on the assumption that the author's experience can serve as a mirror or a model (whether positive or negative) for prospective readers.

2) A second category consists of "**angry pathographies**." Authors of these are motivated by a strong need, based on personal experience, to point out deficiencies in various aspects of patient care. Nearly always, these are deficiencies of *empathy*. As one pathographer observes about her lengthy hospitalization, "I was no longer afraid of the disease, but of the system." Pathographies of this kind are important in alerting all of us to important problems

in medical practice. They vividly depict how an ill person today can be at the same time the beneficiary and the victim of a healthcare system whose very excellence -its superb technological and pharmacological achievements- is at the same time potentially dehumanizing.

3) A third type of narrative, the "**alternatives pathography,"** is also critical of our medical system, but without angry denunciations or doctor- censuring. Like their angry counterparts, these pathographies stem from dissatisfaction with medicine. They differ in that the author is concerned not so much with criticizing traditional medicine as with finding alternative treatment modalities. One can find pathographies about every conceivable kind of alternative. A surprising number of authors describe how they combined conventional treatment with one or several alternative therapies, most without telling their doctors. This group of pathographies can be invaluable in alerting physicians to the appeal of alternative medicine and to the specific treatments that attract patients with particular illnesses.

4) A fourth and very recent group, which might be called "**ecopathography,"** links a personal experience of illness with larger environmental, political, or cultural problems. In these books, illness (usually AIDS, certain cancers, or chronic fatigue syndrome) is perceived as cultural disease, "the product of a toxic environment," as one author observes. The motive of the authors of ecopathographies is prophetic: they are warning the rest of us that their illnesses are the signs and symptoms of much larger problems confronting our culture as a whole. As Kat Duff writes in her pathography, "Illness is the shadow of Western civilization, the antithesis of the rampant extraversion and productivity we so value."'

(From Anne Hunsaker Hawkins, “Pathography: patient narratives of illness”).

REVIEW OF HUNSAKER’S Reconstructing Illness BY ALFRED FRANK

Reconstructing Illness: A Study of Pathographies is the culmination of a series of articles that Anne Hunsaker Hawkins has written over the past decade about pathographies. She adapts this term from Freud's original usage to refer to "an autobiographical or biographical narrative about an experience of illness" (p. 178). "Pathography," Hawkins says, "restores the person ignored or canceled out in the medical enterprise, and it places that person at the very center. Moreover, it gives that ill person a voice" (p. 12). Hawkins presents pathographies as complementary to the *medical history* of the patient. While the medical chart concerns illness as "a particular biomedical condition," the pathography describes how an experience was understood (p. 12). In place of the chart's "present symptoms and body chemistry," the pathography situates illness in the author's life and reflects on "the meaning of that life" (p. 13). Against the impersonal "objectivity" of the chart, pathographies are authored by particular persons who are directly affected by the events they relate.

Truth is a perilous ideal in both the experience of illness and autobiography. To describe the kind of truth pathographies offer, Hawkins uses Robert Lifton's concept of ***formulation*****.** Lifton sought a concept to describe how survivors of Hiroshima reestablished a connection between themselves and others, regained a sense of meaning

in their lives, and reaffirmed a capacity for change. *Formulation*, as Hawkins uses the term, "involves the discovery of patterns in experience, the imposition of order, [and] the creation of meaning"—all with the purpose of mastering a traumatic experience and thereby re-establishing a sense of connectedness with objective reality and with other people" (p. 24). The idea of imposing order on chaotic trauma is particularly important to Hawkins's notion of what a pathography does for its author. Hawkins reads pathographies not for reportorial accuracy but to understand the prevalent myths and metaphors used by all ill persons, not just writers, to formulate their experiences.
… In terms of **authorial intent**, early pathographies tended to be testimonials" that combined personal and practical advice to others suffering the same illness. In the 1970s a shift occurred, to more "angry" pathographies, with medical errors and mistreatment being prominent topics. A third and more recent intent is recording and recommending alternative treatments.

A complementary schema differentiates pathographies according to their dominant myths and metaphors. Here the principal forms are:

- pathographies based on a metaphor of rebirth or regeneration,
- those describing illness as a battle, and, finally,
- Those describing illness as a journey, which in turn has alternative mythic types.

In discussing these metaphors Hawkins takes issue with Susan Sontag's rejection of metaphorical thinking about illness. She points out that Sontag begins *Illness as Metaphor* with one of the most elaborate and frequently quoted metaphors of illness: travel to a foreign country. Hawkins, like other sympathetic critics of Sontag, believes the issue is not to eliminate all metaphors but to find the most enabling metaphors. Pathographies are a storehouse of metaphoric possibilities that can teach both clinicians and ill persons how different metaphors enable or disable particular authors in their formulations of experiences of illness.

Both these typologies of pathographies —by intent and by dominant metaphor— are used to discuss t**hree major substantive themes**.

1) First, Hawkins explains the late-twentieth-century emergence of pathographies through their relation to the religious conversion narratives that enjoyed a parallel popularity in earlier centuries.
2) Her second theme is the description of death and dying in pathographies, and how the diversity of ways of living through death suggests the impossibility of any single contemporary art of dying.
3) Finally, Hawkins discusses the increasing number of pathographies that describe and recommend "alternative" treatments, either as complementary to medical care or substituting for it. Here she uses pathographies as a cultural indicator that shows a more open-market, consumer orientation toward health services.

Hawkins writes frequently of enabling and disabling myths and metaphors, but she wisely uses these terms loosely, recognizing that pathographies teach the difficulty of judging the decisions others make for living through their illness. The value of giving ill persons a voice in pathographies lies in elucidating the complexity of the lived experience of the ill and their care-givers.

SCRIPTOTHERAPY: A term proposed by Suzette Henke to signal the ways in which autobiographical writing functions as a mode of self-healing, scriptotherapy includes the processes of both "writing out and writing through traumatic experience in the mode of therapeutic re-enactment" (n.p.). Henke attends to several twentieth-century women's life narratives that focus on such childhood trauma as incest and abuse, which adult narrators—for example, Anaïs Nin and Sylvia Fraser—record in order to both heal themselves and reconfigure selves deformed by earlier abuse.

SELF-HELP NARRATIVE. This genre of everyday narrative requires people to publicly tell stories of some form of addiction or dependency from which they are seeking recovery. The formulaic pattern of the self-help narrative involves a fall into dissolution and self-indulgence, alienation from a community, "hitting bottom," recognition of the need for help, renunciation of the substance or behavior, and, with trust in a higher power, recovery of a truer postaddiction self. Charlotte Linde describes how this formula reflects a "coherence system" involving "systems of assumptions about the world that speakers use to make events and evaluations coherent" (11). For instance, in Alcoholics Anonymous narratives, as Robyn R. Warhol and Helena Michie argue, "a powerful master narrative shapes the life story of each recovering alcoholic, an autobiography-in-common that comes to constitute a collective identity for sober persons" (328).

TESTIMONIO. The term in Spanish literally means "testimony" and connotes an act of testifying or bearing witness legally or religiously. John Beverley defines *testimonio* as "a novel or novella-length narrative in book or pamphlet . . . form, told in the first person by a narrator who is also the real protagonist or witness of the events he or she recounts, and whose unit of narration is usually a 'life' or a significant life experience" ("Margin at the Center," 92–93). In testimonio, the narrator intends to communicate the situation of a group's oppression, struggle, or imprisonment, to claim some agency in the act of narrating, and to call upon readers to respond actively in judging the crisis. Its primary concern is *sincerity of intention*, not the text's literariness (94). And its ideological thrust is the "affirmation of the individual self in a collective mode" (97).

TRAUMA NARRATIVE. A mode of writing the unspeakable. Nancy Ziegenmeyer and Larkin Warren define what it means to witness in the following terms: "to speak out, to name the unnameable, to turn and face it down" (218). But speaking the unspeakable involves the narrator in a struggle with memory and its belatedness, for, as Cathy Caruth notes, "the experience of trauma . . . would thus seem to consist . . . in an inherent latency within the experience itself" (7–8). This latency of traumatic memory, and the way in which "to be traumatized is precisely to be possessed by an image or event," manifests itself in the psychic delay of memory's temporality and the crisis of its truth (4–5). As Caruth asserts, "the fundamental dislocation implied by all traumatic experience" lies in "both its testimony to the event and to the impossibility of its direct access" (9). Leigh Gilmore, discussing recent studies on trauma by Caruth and Felman and Laub, notes that "the subject of trauma refers to both a person struggling to make sense of an overwhelming experience in a particular context and the unspeakability of trauma itself, its resistance to representation" (Limits of Autobiography, 46). Observing that the Greek root of trauma is "wound," Gilmore stresses in the experience of trauma its self-altering or self-shattering character and the centrality of difficulties in attempting to articulate it (6).