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1 Introduction

The purpose of this Element is to offer a survey of the field of pathographies of mental illness. Despite being one of the largest areas of pathography,[1] a foundational survey has not been written – until now.[2] In doing so, this Element will focus on a substantial number of major mental illnesses, including depression, bipolar disorder, schizophrenia, substance use disorders, borderline personality disorder, conduct disorder, antisocial personality disorder, autism spectrum disorder, and eating disorders.

A distinguishing feature of this Element is that it will pair material from the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*)[3] with classic or contemporary pathographies of mental illness. The language and findings of the *DSM* are the result of tens of thousands of scientific studies, with large data sets, while the episodes recounted in a given pathography are the result of introspective reflection (N = 1). A central claim here is that both of these forms of knowledge – evidence and experience – are valuable. If scientific evidence points to key trends (i.e., findings) with regard to a particular mental illness, which are necessary for diagnosis, pathographies lift up common themes (i.e., insights), which can be useful for treatment and policy.

It is worth pointing out that pathographies, both because they are a snapshot in time and also because they tend to be written by patients, can sometimes present misleading, outdated, or incorrect clinical information. This is another reason why it is important to pair pathographies with the most recent version of the *DSM*. The fact that the *DSM* has undergone many revisions underscores that what we understand mental illness to be is socially and historically conditioned. Like pathographies, all versions of the *DSM* are snapshots in time, reflecting the scientific thinking of a particular moment, also embedding assumptions about race, gender, and other cultural considerations.

In this Element, there will be an emphasis on the classic texts in the field, which leads to a limitation – namely, most of these books have been written by wealthy, educated, White persons. As Meri Nana-Ama Danquah observes in *Willow Weep for Me*, her pathography on depression:

> I have noticed that the mental illness that affects White men is often characterized, if not glamorized, as a sign of genius, a burden of cerebral superiority, artistic eccentricity – as if their depression is somehow heroic. White women who suffer from mental illness are depicted as idle, spoiled, or just plain hysterical. Black men are demonized and pathologized. Black women with psychological problems are certainly not seen as geniuses. . . . When a Black woman suffers from a mental disorder, the overwhelming opinion is that she is weak.[4]

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Still, few persons of color have written pathographies. For some mental illnesses, there are none. To somewhat mitigate this bias, an appendix is offered of more recent pathographies with an emphasis on persons of color.

The structure that follows is straightforward, beginning with a discussion of the genre of pathography and then focusing on various mental illnesses, pairing, as noted, pathographies with *DSM* material. In each case, attention is called to the way in which the pathography sheds light on or concretizes clinical criteria, providing a richer understanding of the criteria and illness. In conclusion, key personal themes are offered that cut across the pathographies, demonstrating the value of reading this kind of material for practical use.

2 What Is Pathography?

In medical humanities, the classic text on pathography is Anne Hunsaker Hawkins's *Reconstructing Illness*.[5] She describes the book as "a study of the myths, attitudes, and assumptions that inform the way we deal with illness."[6] Her method is to analyze autobiographies and biographies of illness to make recommendations about contemporary clinical practice. Thus, Hawkins takes pathographies to be autobiographies and biographies of illness – in other words, narratives of illness: path (= illness) + graphy (= narrative). As medical humanities has developed, what has been understood as pathography in terms of genre has broadened (especially with the development of graphic medicine[7]) in that pathography now includes, but consists of more than, narrative.

Of note, Hawkins points out that her own personal experience led her to this area. While she was writing a dissertation on spiritual autobiographies, her father suffered a ruptured cerebral aneurysm that left him partially paralyzed. Impacted by her father's situation, she became interested in the accounts of other people's experiences of illness. Hawkins was particularly moved by Oliver Sacks's *Awakenings*,[8] and it was in this book that she first encountered the word "pathography."[9] When Sacks used the term, he cited Sigmund Freud.[10] As she continued reading pathographies while also doing her graduate work, Hawkins began to wonder "if contemporary pathographies, like the spiritual autobiographies [she] studied, revealed significant truths about the cultures and value systems from which they sprang."[11]

After graduate school, in 1990, Hawkins joined the Humanities Department at the Pennsylvania State University College of Medicine, where she found that her work had a new practical dimension. Her students and colleagues assumed that the study of literature could make medical students into better doctors, an assumption that she came to endorse: "It is in restoring the

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patient's voice to the medical enterprise that the study of pathography has its greatest importance and offers its greatest promise. . . . It is surely no accident that the appearance of pathography coincides with the triumph of scientific technological medicine."[12] She adds: "Pathographies make such problems vividly and immediately real for us, and thus they have a significant part to play in the movement towards a patient-centered medicine."[13]

In a follow-up essay to her book, Hawkins points out that while the writing of pathographies is, for the most part, a phenomenon that begins in the twentieth century, an early example can be observed in John Donne's seventeenth-century *Devotions Upon Emerging Occasions*, where he explores his experience of illness, from diagnosis to recovery. She adds that, throughout history, there are other examples of pathography-like material that include descriptions of illness, but few take the author's own experience as the central subject, the key characteristic of contemporary pathographies.[14]

Hawkins notes that *Reconstructing Illness*, as a scholarly text, is a metapathography. That is, if pathographies are narratives of illness, she is offering an analysis of these narratives. Her basic argument is that contemporary pathographies tend to fall into three narrative patterns: journey, battle, and rebirth.[15] Hawkins offered other categories elsewhere.[16]

In a review of Hawkins's *Reconstructing Illness*, Arthur Frank, who himself wrote a classic pathography in medical humanities,[17] picks up on the question of truth. He asks: Is the idea that the case reports written by doctors are false but the pathographies written by patients are true? No, quoting Hawkins, Frank writes: "each one distorts, each one tells the truth."[18] Although generally praising Hawkins, Frank concludes by noting that he wishes Hawkins would have provided "a unifying meta-myth" of pathographies, even though he realizes that it was not her intention. Instead, out of respect for patients, she wanted them to be heard in their own voices. Frank writes: "Here is a central dilemma in scholarship about both the experience of illness and medical ethics. If the ethical commitment is to allow ill persons their own voices, how does one write about these voices without appropriating them?"[19] Frank would continue to work on this question in subsequent publications.[20]

Although the most common genre of pathography is memoir, poetry is another important medium for conveying experiences of illness. In "Patient Poets: Pathography in Poetry," Marilyn McEntyre notes that while a great deal of attention has been given to narrative medicine, "poetry opens a very different window from narrative, emphasizing discontinuity, surprise, experiential gaps, and the uneasy relationship between words and the life lived in the body."[21] She adds that poetry teaches us to read and listen differently, emphasizing that

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"[i]t can be hard to remember that life is not 'story,'" for "things do not happen in sequences or well-constructed plot lines."[22]

In explaining what poetry adds to pathography, McEntyre says: "We can learn to attend to their images, their puzzling line breaks, their shifts of focus – to all the techniques we call 'literary' – as keys to conditions of body and mind that could not be adequately articulated in any more discursive way."[23] McEntyre affirms that "[s]uffering is a truth that must be told 'slant,' as Emily Dickinson advised," adding that "[i]t can be conveyed, but not in simple declarative sentences, and not on scales of one to ten."[24] McEntyre also suggests that poems have practical/clinical value because "everyone who speaks encodes. All dialogue has its pauses, metaphoric detours, apparent irrelevancies, subtexts, allusiveness."[25] She continues: "Reading them well is praxis, and practice for the challenging, subtle, peculiar, rewarding work of reading what is inscribed in the human faces and voices and bodies that come into our clinics and classrooms in the hope of being healed."[26]

2.1 Narrative Ethics

Before moving on to the subject of this Element – the voices of illness as recorded in pathography – a brief discussion is needed to distinguish the field from that of narrative ethics. Narrative ethics is broader than medical ethics, as its concerns include but are beyond medicine. A critical mass of scholarship on narrative ethics within medicine began to appear by the early 2000s. In *Stories Matter*, Rita Charon and Martha Montello offer an edited volume (published in 2002) of key thinkers who helped to establish narrative ethics within and alongside bioethics, medical humanities, literature and medicine, and more. They write: "Narrative ethics arose as doctors, nurses, ethicists, and patients found themselves taking seriously their acts of reading, writing, and telling. From patients' pathographies and caregivers' stories from practice to ethicists' written cases, what unified these early efforts was the recognition of the centrality of narrative in the work of health care."[27] So, the genre of pathography predates – and also helped to establish – narrative ethics within medical circles.

What is narrative ethics? Charon and Montello note that, in their volume, there is not a codified list of propositions that define narrative ethics. Rather, they offer a number of "exemplars" that display what has been called "a narrativist turn" in various fields that recognizes "the extent to which perceptions are embedded in their telling, realizing human beings' reliance on storytelling to get their bearings in life, and acknowledging the innately narrative structure of human knowledge and provisional truth."[28]

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In a subsequent essay, Montello described narrative ethics as focusing on *how* people come to particular moral decisions as distinguished from *what* moral decisions they make. Drawing on Martha Nussbaum, Alasdair MacIntyre, and Rebecca Goldstein, Montello refers to this focusing on *how* as exploring the "mattering maps" of people. Mattering maps are "a projection of its inhabitants' perceptions . . . [of] what matters to [a person], what matters overwhelmingly."[29] Montello adds that what matters to different people in the same situation can vary greatly, as can what matters to a person over the course of their lifetime. Therefore, what makes narrative ethics different from, say, usual applications of principlist bioethics is that narrative ethics pays much more attention to issues such as context and emotions.

After defining and describing what pathographies are, and how they differ from narrative ethics, an important question arises: In addition to providing interesting reading, "Why do pathographies matter?" Proposed reasons can be associated with different groups:

- *Authors*: Any serious illness is psychologically as well as physically traumatizing. Organizing what seems to be a chaotic experience into a structured written expression can help to facilitate a sense of control and personal insight. Pathographies matter because they help sufferers make sense of their illness.
- *General Readers*: For those sharing the same condition as the author, the recognition of a similar experience helps to cut through feelings of isolation. Also, the anecdotal perspective can provide general information on the course and treatments of particular illnesses. Pathographies matter because they can provide a practical and existential road map for others.
- *Health Care Professionals*: As unique "windows" into the patient's medical encounters, pathographies can provide insights that would otherwise remain hidden. Pathographies matter because they can prompt self-reflection among doctors, nurses, and others, providing an important tool for improving patient care.

We now turn to examples of pathographies of mental illness and the ways in which they illustrate the descriptions of mental illness found in the *DSM*.

3 Depression

3.1 Darkness Visible

Depression is probably the most well-known mental illness, for it seems to be the most relatable. Who has not felt sadness from time to time? But depression is also often misunderstood because sadness is not depression.

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In *Darkness Visible,* William Styron, one of the most influential American fiction writers of the twentieth century, writes about his own depression, near suicide, and hospitalization. A key objective of the book is to destigmatize suicide. Through his own experience, Styron proposes that when people die by suicide, this is not because they are weak, selfish, or immoral. Rather, it is because of pain. Because the pain is so intense and so unrelenting, they see no other option.

Styron suggests that depression is not merely feeling down or "the blues." It is a much more active experience. "For me," he writes, "the pain is most closely connected to drowning or suffocation."[30] He adds:

> It may be more accurate to say that despair, owing to some evil trick played upon the sick brain by the inhabiting psyche, comes to resemble the diabolical discomfort of being imprisoned in a fiercely overheated room. And because no breeze stirs this caldron, because there is no escape from this smothering confinement, it is entirely natural that the victim begins to think ceaselessly of oblivion.[31]

Most people suffering from depression have difficulty sleeping and eating, finding it hard to get out of bed in the morning. Styron, too, had difficulty sleeping, but his depression grew worse as the day progressed, characterized by a mounting stifling anxiety. Other common symptoms (all experienced by Styron) include the inability to concentrate, the loss of rational thought and perspective, confusion, memory problems, panic, difficulty speaking, loss of libido, and an inability to experience pleasure or joy.

What caused Styron's depression? Why did it happen when it did? Styron thinks that such questions really do not have answers and that the best that one can do – for oneself and for others – is to engage in "wise conjecture."[32] In his own case, Styron thinks that his depression was multifactorial: relating to his genetics, the death of his mother while he was a teenager, unhappiness with his writing, turning age sixty, and, perhaps most significantly, his experience of alcohol withdrawal. For decades, Styron would drink throughout the day, in an attempt to calm his anxiety. Drinking also seemed to help his creative process. But his stomach condition forced him to quit drinking – and this might be thought of as the trigger that initiated his depression.

How did Styron improve? He was critical of medication and therapy, but, strikingly, he was very positive about his stay in a psychiatric hospital. He felt that it was time that healed him – not medication or therapy – and that what he needed most was a safe place to be. This contrasts significantly with the negative image of psychiatric hospitals in films (based on books) such as *One Flew Over the Cuckoo's Nest*[33] as well as *Girl, Interrupted*,[34] which depict psychiatric hospitals as oppressive. For Styron, although the hospital was not

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a luxurious interlude, and while he found parts of it annoying (e.g., therapeutic activities), it nevertheless was a profoundly positive experience for him.

As Hawkins noted, no pathography offers an unfiltered vision of truth. They offer, to use her term, "formulations,"[35] as these narratives are crafted for publication. Another way of saying this is that they offer a perspective. This is demonstrated strikingly in a brief reflection written by Rose Styron, William Styron's wife. According to William, it was his idea to go to the psychiatric hospital, but this does not coincide with Rose's recollection. Rose includes notes from their daughter, Polly, who was with them that night, and these notes were written down shortly after the events unfolded:

> So, I guess I should write this down, or I won't believe it. I came to the house Friday evening because I heard that Dad had had a terrible night on Thursday and that he and Mum were fairly shaken. I was prepared for a morbid gloom, but not for what the night actually turned out to be. When I went upstairs to his room he was lying there, with his long gray hair all tangled and wild. I took his hand, which was trembling. "I'm a goner, darling," he said, first thing. His eyes had a startled look, and seemed to be not quite there. His cool, trembling hands kept fumbling over mine. "The agony's too great now, darling. I'm sorry. I'm a goner." . . . He raved about his miserable past and his sins and the waste of his life and how, when they published the scandal of his life, we should try not to hate him. . . . "You'll hate me for what I am going to do to myself. My head is exploding. I can't stand the agony anymore." . . . When Mum finally came upstairs, as he held me next to him with his eyes closed, I mouthed the word "HOS-PIT-AL to her."[36]

This is very different from William's account; he emphasizes his own strength and initiative in deciding to go to the hospital. But, as a reader, taking into account his daughter's notes of the events recorded so soon after they happened, the perspectives of Rose and Polly seem more compelling. This raises the question: Why did William write the account the way he did? Also, William does not mention a subsequent relapse. Why? Was he trying to serve as an inspiration to others? Was he ashamed? Was he trying to nurture agency among persons suffering from depression? What are the ethical and moral responsibilities of representation?

3.2 Clinical Information

The *DSM-5-TR* has a section on depressive disorders, which includes major depressive disorder. The diagnostic criteria for major depressive disorder include five or more of the following symptoms during the same two-week period:

1. Depressed mood
2. Diminished pleasure and interest

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3. Significant weight loss or weight gain
4. Insomnia or hypersomnia
5. Psychomotor agitation or retardation
6. Fatigue
7. Feelings of worthlessness or excessive guilt
8. Diminished ability to concentrate or make decisions
9. Recurrent thoughts of death or suicidal ideation or plans[37]

To make this diagnosis, one of the symptoms must be either depressed mood or loss of pleasure or interest. Also, the symptoms must cause distress or impairment, must not be attributed to another medical condition or substance, and cannot be better explained by another psychiatric disorder. There must never have been a manic or hypomanic episode, unless that episode can be attributed to the use of a substance, medication, or other medical condition.[38]

Styron clearly experienced most of the clinical criteria for major depressive disorder. Symptoms that stood out were diminished pleasure and interest, recurrent thoughts of suicide, excessive guilt for wishing to die by suicide (e.g., "You'll hate me for what I am going to do!"), and diminished ability to concentrate, resulting in the loss of his ability to work productively, which was so central to his identity.

A key claim of *Darkness Visible* is that depression cannot be understood by persons who have not experienced it, that it is a sui generis experience. If, for example, a person is color-blind and they cannot see the color yellow, there is no way to describe the color of a lemon to them, for yellow cannot be described in any other terms. And this is what Styron thinks depression is like: If you have not experienced it, you just cannot understand it. This is underscored in the pathography when Styron describes his interactions with his psychiatrist, especially with his disbelief as to his psychiatrist's inability to understand his complete lack of libido.

It is one thing to know the clinical criteria for depression; it is another to understand how the illness is experienced in a depressed person's life. Although some of the material in *Darkness Visible* is dated – for example, the cultural stigma associated with depression is no longer the same as it was when Styron was writing – what Styron gives us, as a professional writer, is the gift of a description of an inner experience that is almost not understandable by outsiders.

4 Bipolar Disorder

4.1 An Unquiet Mind

Like Styron's *Darkness Visible*, Kay Redfield Jamison's *An Unquiet Mind* is an acclaimed classic among pathographies of mental illness, and a highly

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recommended resource in the literature of bipolar illness. Although depression is a condition more commonly found relatable, experiences of mania or psychosis are less so. A layperson asked to describe the symptoms of bipolar illness would typically have difficulty in doing so. Sometimes the words "borderline" and "bipolar" are confused, as there is a tendency to incorrectly associate borderline with being manic, which is often a symptom of bipolar disorder. Also, borderline is a personality disorder, while bipolar is a mood disorder.

Like Styron, Jamison has led a very productive life because of her socioeconomic class and strong social connections. Although she considered going to medical school, she instead chose graduate school in order to study clinical psychology. Jamison correctly intuited that the structure of medical education was too rigid for her. However, despite having studied the illness, her insight during the early years of its manifestations was limited. Even when she did concede that she was ill, she resisted treatment because, in part, she saw the illness as "an extension of myself."[39] She writes:

> My manias, at least in their early and mild forms, were absolutely intoxicating states that gave rise to great personal pleasure, an incomparable flow of thoughts, and a ceaseless energy that allowed the translation of new ideas into papers and projects. Medications not only cut into these fast-flowing, high-flying times, they also brought with them seemingly intolerable side effects. It took me far too long to realize that lost years and relationships cannot be recovered.[40]

Because Jamison worked as a professor at a medical school, some of her manic episodes were extremely beneficial, as she could write a journal article in a single night, making it easy for her to produce enough publications for tenure. There were downsides too. Sometimes, when she was on medication, she was not able to read because of side effects. This caused her a great deal of suffering because her intellectual life was so central to her identity.

Most pathographies tend to offer lessons learned – often about the importance of therapy or medication – and Jamison creatively conveyed her own such lessons by creating a list of "Rules for the Gracious Acceptance of Lithium into Your Life":

1. Clear out the medicine cabinet before guests arrive for dinner or new lovers stay the night.
2. Remember to put the lithium back into the cabinet the next day.
3. Don't be too embarrassed by your lack of coordination or your inability to do well the sports you once did with ease.

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4. Learn to laugh about spilling coffee, having the palsied signature of an eighty-year-old, and being unable to put on cuff links in less than ten minutes.
5. Smile when people joke about how they think they "need to be on lithium."
6. Nod intelligently, and with conviction, when your physician explains to you the many advantages of lithium in leveling out the chaos in your life.
7. Be patient when waiting for this leveling off. Very patient. Reread the Book of Job. Continue being patient. Contemplate the similarity between the phrases "being patient" and "being a patient."
8. Try not to let the fact that you can't read without effort annoy you. Be philosophical. Even if you could read, you probably wouldn't remember most of it anyway.
9. Accommodate to a certain lack of enthusiasm and bounce that you once had. Try not to think about all the wild nights you once had. Probably best not to have had those nights anyway.
10. Always keep in perspective how much better you are. Everyone else certainly points it out often enough, and, annoyingly enough, it's probably true.
11. Be appreciative. Don't even *consider* stopping your lithium.
12. When you do stop, get manic, get depressed, expect to hear two basic themes from your family, friends, and healers:
    - But you were doing so much better, I just don't understand it.
    - I told you this would happen.
13. Restock your medicine cabinet.[41]

This list, while sad and humorous, captures many of the practical difficulties of living with bipolar illness.

4.2 Clinical Information

In the *DSM-5-TR*, there is a section on bipolar and related disorders. It is between the section on depressive disorders and the section on schizophrenia spectrum and other psychotic disorders, recognizing that bipolar disorders are "a bridge between the two diagnostic classes in terms of symptomology, family history, and genetics."[42]

The focus here is on bipolar I. To make this diagnosis, there must be at least one manic episode. A manic episode involves an abnormally elevated, expansive, or irritable mood, along with increased energy or activity, lasting for at least a week. During this period, there must be three (or more) of the following symptoms (or four if the mood is only irritable):

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