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NARRATIVES OF
UNDIAGNOSABILITY
*Chronic Fatigue
Syndrome Life-Writing
and the Indeterminacy
of Illness Memoirs*

GASTON FRANSSSEN



ABSTRACT: There is a distinct tendency within the field of psychological and psychiatric literature to cite illness memoirs as exemplary sources of insight into the subjective dimension of how illness is experienced. However, the epistemological reliability of such sources remains open to question: Do such sources indeed offer meaningful insights into the authentic experiences of patients and in doing so, provide effective coping and self-management strategies, or are they merely literary and/or popular constructs, the value and meaning of which are fundamentally indeterminate? In this contribution, I analyze three such memoirs: Floyd Skloot's (1996) *The Night-side*; Rik Carlson's (2004) *We're Not in Kansas Anymore*; and Julie Rehmeyer's (2017) *Through the Shadowlands*—all describing individual experiences of the symptoms of chronic fatigue syndrome (CFS). As CFS remains a puzzling and contested illness, an analysis of these narratives offers the opportunity to explore the presupposed values as well as the limitations of illness life-writing. In this article, I map the academic debate on the epistemological value of illness narratives and chart the discussion on CFS since the early 1990s. Subsequently, I propose a double reading—a “medical” reading and a “literary” reading—of the memoirs considered. Finally, I suggest that the inherent indeterminacy of CFS life-writing is an important quality that contributes to a deeper understanding of living

and coping with chronic, as yet medically unexplained illnesses. Reading illness memoirs, I conclude, reveals the rhetorical and cultural dimensions, as well as the ambiguities and uncertainties of such experiences.

KEYWORDS: Narrativity, chronic fatigue syndrome, life-writing, patient experience, memoir, indeterminacy

B EING DIAGNOSED WITH a chronic illness has a profound impact on an individual's self-image: As a long-term patient, one is forced to redefine one's relation to the world and to reconsider one's life story. Fittingly, sociologist Michael Bury (1982) characterizes chronic illness as a “biographical disruption” (p. 167). If an illness is considered to be medically unexplainable, or if a diagnosis is lacking altogether, the patient's predicament deepens even further. How can patients be expected to make sense of their symptoms, and to cope with the biographical disruptions they entail, if their condition is fundamentally indeterminate, without a known cause, treatment, or prognosis? When symptoms lack any sufficient medical explanation, patients face a

profound narrative and existential crisis. Therefore, it is essential to forge a deeper understanding of the impact of such a biographical disruption on their life stories and to explore strategies that can help them to cope with their illness.

In the psychological and psychiatric literature, as well as in the realm of self-help, there is a tendency to cite illness memoirs as exemplary sources of insight into the subjective dimension of illness. Such memoirs, it is suggested, might provide access to personal experiences of illness and, in doing so, offer the prospect of effective treatment options or coping strategies. According to Sidonie Smith and Julia Watson (2001),

narratives of illness and disability proffer stories of loss and recovery at the same time that they function as a call for increased funding for research, new modes of treatment, and more visibility for those who have been assigned the cultural status of the unwhole, the grotesque, the uncanny. (p. 108)

It is this assumption that also fuels the use of illness memoirs in diverse forms of bibliotherapy (which, in general, entails the prescription of reading books, with or without professional guidance, to improve health or well-being) (Hynes & Hynes-Berry, 2019). In fact, works of memoir and (auto)fiction have been widely used to facilitate individuals coping with, among other things, grief, depression, eating disorders and anxiety, but also with chronic conditions of a somatic nature, such as respiratory and heart disease or diabetes (Kim, 1999; Brewster, 2009; McAllister, Brian, Alexander, & Flynn, 2014). Although there is little research on the efficacy of this type of bibliotherapy as a form of self-management training, and although it has been pointed out that some reading materials might even have negative effects on the behavior and quality of life of some patients groups (Troschianko, 2018), there is thus a longstanding and widespread conviction, among patients as well as health-care professionals, that memoirs and (auto)fictional works of illness have potential as therapeutic, (psycho)educational or practical health-care tools.

Other scholars, however, suggest that such uses of illness memoirs as sources of health-related information and guidance is questionable. In

their analysis of memoirs of depression, Jennifer Radden and Somogy Varga (2013) argue that “autobiographical writing entails an act of personal self-shaping that springs from ordering experience *within* specific literary laws of closure and coherence, dramatic, and rhetorical devices and conventions” (p. 102, emphasis in original). Consequently, illness memoirs should be considered “problematic and ambiguous, their meanings remaining . . . *indeterminate*” (Radden & Varga, 2013, p. 102, emphasis in original). Such publications, Radden and Varga (2013) warn, “may tell us more about the discourse on depression within the medium of literature than about the concrete and ‘raw’ experience of depression itself” (p. 100). This critical perspective on the value of illness memoirs, of course, would also place important limitations on their bibliotherapeutic potential: if their “meanings” are indeed indeterminate, or offer readers mostly insights into literary conventions instead of into the subjective dimensions of illness, then their value as educational, therapeutic or self-management resources seems questionable at the least.

In the context of medically unexplained chronic illness, the question of the potential value of illness memoirs becomes particularly salient, yet also precarious. Can such publications provide readers with much-needed insights into these enigmatic illness experiences, or do they, as aesthetic products of literary and cultural conventions, merely frustrate the need for clear-cut answers and effective advice? In this article, I explore this issue with a specific focus on the memoirs of patients with chronic fatigue syndrome (CFS).¹ My aim is to determine how these memoirs are construed and what the effect is of their formal and semantic qualities on the knowledge they produce. Specifically, I am interested in the relation between the literary (i.e., aestheticized) story these authors offer and the lived narratives of CFS patients.

My analysis proceeds from two contradictory assumptions that dominate current research on illness memoirs. The first assumption is that such memoirs have an important role to play in healthcare as, in contrast to medical case histories, they offer insights into the lived experiences of patients. The second assumption is that, because

of their literary nature, such insights are inherently unreliable, as they have been written making use of a variety of narratological, rhetorical, and stylistic devices, all intended to produce specific effects on readers. It is this quality—which I here refer to as “literary”—that, according to some scholars, undermines the epistemological status of autopathography. In the second section, I will elaborate upon, and subsequently test, these two main assumptions via an analysis of three CFS memoirs: Floyd Skloot’s (1996) *The Night-side*, Rik Carlson’s (2004) *We’re Not in Kansas Anymore*, and Julie Rehmeyer’s (2017) *Through the Shadowlands*. By doing so, I will demonstrate how a literary studies perspective can contribute to research on illness narratives and the knowledge they produce. As I will show, such a perspective offers insights, not only into the role of ambiguity and indeterminacy in *writing about* illness, but also into the *experience of* illness.

In my analysis, I take my cue from Lilian R. Furst’s (2012) “medical humanities methodology” (p. xii), as proposed in her book *Idioms of Distress: Psychosomatic Disorders in Medical and Imaginative Literature*. Furst (2012) combines insights from medical research with literary close reading, claiming to offer “dualistic readings in which the partly speculative medicalized perception of an overt text of bodily disturbance is partnered by a humanistic perspective that interprets the literal as a metaphoric figuration of a psychological subtext” (p. xii). Similarly, I pair a medical sociological and psychological perspective with literary analysis, however, my approach differs from that of Furst in one important respect: Whereas Furst interprets somatic symptoms described in literary texts as symbolic manifestations of a strictly psychological problem, I analyze the selected memoirs as literary evocations of an illness history that is experienced somatically. In other words, it is not my intention to reduce these “texts of bodily disturbance” to an underlying psychological issue, but rather to approach them as literary texts that signify what it means to live with CFS. For this reason, my reading can be characterized as a poststructuralist analysis of the language of illness. In line with Roland Barthes (1985, p. 279), I focus on “diagnostics” as a process of translation

of medical symptoms and experiences in linguistic signs, as well as on the shifts that such a translation instigates. This approach will be operationalized as a “double” reading: First, I analyze to what extent the memoirs can be considered exemplary narratives of CFS in light of medical, sociological, and psychological insights into the condition. Second, I turn my attention to the literary aspects of the memoirs and highlight how narratological, rhetorical, and stylistic devices influence our knowledge of CFS.

ILLNESS NARRATIVES AND AUTOPATHOGRAPHIES

In the fields of life-writing studies, disability studies, and the medical humanities, memoirs and other (auto)biographical texts are often seen as valuable sources of insight into the impact illnesses have on the lives of patients. Among others, Arthur W. Frank’s (1995) *The Wounded Storyteller: Body, Illness, and Ethics*, G. Thomas Couser’s (1997) *Recovering Bodies: Illness, Disability, and Life Writing*, or Mary Ellen Wood’s (2013) *Life Writing and Schizophrenia: Encounters at the Edge of Meaning* are examples of this line of research. Often, such publications focus on memoirs and autobiographies, also labelled “autopathographies” (Hawkins, 1999). However, they also frequently include autofiction or completely fictional works, arguing that these contain echoes of real patient experiences and, conversely, that patients make us of existing narratives or cultural scripts (taken from myths, films, novels, et cetera) when shaping their life stories (Frank, 2012).

This line of research revolves around a narrative conception of identity that postulates that identity is shaped by the stories that individuals create, share, and by which they ultimately live. Such narratives can be expressed in words, as in the case of memoirs or autobiographies, but are also construed implicitly and internally: According to a narrative conception of identity, every individual engages in self-narration, creating a life story in which specific events determine the plot, characters play leading or marginal parts, and experiences are ordered and interpreted (Couser, 1997; Frank, 1994). When confronted with illness or disability,

the life story of an individual is also affected: The self-narrative is interrupted, becomes fragmented, or enters a phase of developmental stagnation. According to Frank (1995), this disruption is experienced as “narrative wreckage” (p. 53). Not only does the illness experience itself possess a narrative dimension; the coping strategies of patients suffering illness can also be understood in narrative terms. “A self that has become what it never expected to be,” Frank (2000) maintains, “requires repair, and telling autobiographical stories is a privileged means of repair” (p. 135).

Frank (1994) has introduced a useful typology of illness narratives, discerning between three “culturally available narrative voices”: “the restitution story, the chaotic story, and the quest story” (p. 5). Restitution narratives are characterized by a straightforward, strictly medical plot: an individual becomes ill, is diagnosed, takes medication or enrolls in short-term therapy, and recovers. Chaos narratives, however, lack such a clear-cut plot. In this case, there is no clear diagnosis, the prescribed treatment plan fails to have effect, or the illness is revealed to be of a chronic nature. As a result, the narrative becomes repetitive, fragmented, or directionless. Lastly, the quest narrative construes the illness experience as a personal challenge or a spiritual journey. What drives the plot of this narrative is not so much working toward bodily recovery, but the mental transformation or growth, in the form of hard-won, new insights into the self, life, or society. These three distinct narrative voices are ideal types; in reality, they are often part of a “narrative mix” (Frank, 1994, p. 19). Illness memoirs, Frank (2012) suggests, are ideally suited for a closer analysis of these different narrative voices: “In memoirs, it is easiest to see the commonly shared stock of narrative resources that are available to represent what become people’s experiences” (p. 40). Frank’s typology has a proven efficacy, providing productive insights into a wide variety of conditions and is thus often evoked, not only by literary studies, but also by scholars of the medical humanities.

However, opinions differ sharply when it comes to the relation between illness narratives and the actual *experiences* of the individuals concerned. On the one hand, there are scholars, such as

Anne Hunsaker Hawkins (1999), who maintain that illness memoirs give a voice to the person “behind” the patient and thus provide access to the subjective dimension of illness. More generally, autobiographies are understood as offering the implicit promise that readers will be granted insights into the experiences of the author, but in the case of autopathographies, this “autobiographical pact” (Smith & Watson, 2001, pp. 8-9) becomes even more manifest. According to Hawkins (1999), in autopathographical writing, “the self-in-crisis” finds a voice, stripping away all “fictions, metaphors and versions of the self” from “a ‘hard’ defensive ontological reality” (p. 17). “Pathography,” Hawkins (1999) concludes, “returns the voice of the patient to the world of medicine . . . and it does so to assert the phenomenological, the subjective, and the experiential side of illness” (p. 12).

On the other hand, there are scholars who claim that the value of memoirs as sources of insight into the experience of illness is undermined by the unreliability of the self-narrative as a subjective reconstruction, the cultural conventions of biography, and the inherent indeterminacy of memoirs as linguistic, aesthetic constructions. In line with Radden and Varga’s (2013) criticism as paraphrased in the introduction, John Hardwig (1997), for example, points out that a written self-narrative is always the product of a process of selection, interpretation, and appropriation, and should thus be considered “epistemically and morally suspect” (p. 50). In a similar vein, Rebecca Garden (2010) warns that both the genre rules of autobiographical writing and the demands of the readers market may well be more determinant of the form and content of illness memoirs than the author’s intention to provide the reader with an authentic account of their illness.

In her insightful overview of the discussion, provocatively entitled “The Limits of Narrative: Provocations for the Medical Humanities,” Angela Woods (2011) takes stock of the ambitious claims of those who underline the epistemological value of illness memoirs and the criticisms of those who question that value. Acknowledging that the study of autopathographies in the context of medical research can indeed be insightful, Woods, however,

cautions researchers to take into account several complicating factors—the indeterminable degree of truthfulness of such stories, their historical and cultural situatedness, and their potentially normative message—as these factors inevitably shape and color the illness experience itself. Specifically, Woods (2011) invites scholars to pay attention to the “formal organization, rhetorical structure and thematic content” of illness narratives, as well as “how [these enable and constrain] the production of certain kinds of narratives in an array of medical and broader cultural contexts” (p. 75). In other words, those who intend to determine the value of autopathographies also need to analyze how the narrative itself is constructed, how it relates to social and cultural contexts, and what its effects might be.

In the case of the three illness memoirs under consideration, the issue of their value as sources of insight and advice is particularly foregrounded. First, the authors themselves are very explicit about their intentions, namely, to shed light on the phenomenon of CFS and to offer advice on how to cope with it. “When I first got sick,” Skloot (1996) writes,

my illness was so poorly understood by the public and media . . . and so mishandled by the medical community, which had trouble diagnosing and believing it, that I felt the need to let them all know what was really involved. (p. 106)

Rehmeyer (2017) presents her book as the product of her work as a “science writer,” its jacket notes further claiming that it “bring[s] scientific authority to a misunderstood disease” (n.p.). Finally, Carlson (2004) suggests that the value of his book lies in the fact that others can use it as a “tool”; “a primer for family and friends, neighbors and employers” (p. 128). As will become clear in the following section, the reception of these memoirs indicates that the authors have succeeded in their intentions: Their stories have been widely accepted as authentic accounts of the experience of CFS symptoms and have come to function as exemplary illness narratives in medical discourse. What exactly, then, are the values—and the limits—of these personal narratives? To answer this question, it is first necessary to situate these memoirs in the context of the societal and medical discussions on

CFS since the early 1990s, as their authors position themselves explicitly within those debates.

THE DEBATE ON CFS

The first experiences of illness described in the three memoirs are strikingly similar. All three authors were productive, successful individuals until the sudden onset of a series of debilitating symptoms: headaches, disordered sleeping patterns, muscle and joint pains, difficulties with thinking and talking, feelings of disorientation, and a profound sense of fatigue (Carlson, 2004, pp. 27-32; Rehmeyer, 2017, p. 27; Skloot, 1996, pp. 8-9). They first associate their symptoms with a serious case of the flu, however, as their malaise continues, over the coming weeks and months, they slowly realize that they are confronting an altogether different illness. After several (mis)diagnoses and ineffective treatment strategies, they each in turn conclude that CFS might be the cause. Skloot (1996) writes in the opening pages of his memoir that “illness must be looked at straight-on, in all its implications” (p. xiii). However, as the authors soon discover, in the case of CFS, such an approach proves to be profoundly difficult because, as Skloot’s fellow sufferer Carlson (2004) notes, it is an “invisible illness” (p. 83, emphasis in original).

The history of CFS is complex and subject to intense debate. Indeed, its exact origins are difficult to pinpoint particularly as, over the centuries, it has been labelled in so many different ways. In a medical publication on myalgic encephalomyelitis (ME) by C. W. Wilson from 1990, it is suggested that the first reference to the illness occurs in 1662, when it was identified as “the Vapours” (Wilson, 1990, p. 481).² While another researcher, S. E. Straus (1991, S2), has uncovered a treatise from 1750 on “febricula,” which lists comparable symptoms. Whatever the origin of the illness may be, there is at least some consensus about the fact that, from the nineteenth century onwards, this complex, chronic illness has increasingly drawn the attention of the medical world as a distinct syndrome. The label ME—a term which, as Olaug Lian and Hilde Bondevik (2015, p. 927) point out, implies that the illness has a somatic nature (muscle ache associated with inflammation of the

brain and spinal cord)—gained popularity in the 1950s. Later, while popular media started to refer to the illness as “Yuppie Flu” during the 1980s, several other names, foregrounding different symptoms and indicating a variety of causes, began to circulate in medical discourse: chronic fatigue immune dysfunction syndrome, Epstein-Barr viral syndrome, post-viral fatigue, chronic candidiasis, Akureyri disease, and Icelandic disease (Straus, 1991; Ware, 1992). In the early 1990s, Edward Shorter (1993, p. 6) observes, these diagnostic variations began to converge around the label of CFS.

Also in the 1990s, alongside the continuing search for somatic causes, researchers began to consider psychogenetic explanations for chronic fatigue in combination with medically unexplained physical complaints (van Geelen, 2010). This shift in the CFS debate marks an increase in the attention being paid to the psychological dimensions of the illness. Currently, most medical psychological/psychiatric textbooks—for example, the *Oxford Handbook of Clinical Psychology* (Woolfolk & Allen, 2011, p. 352), or the *Textbook of Psychosomatic Medicine* (Sharpe & O’Malley, 2019)—include information on CFS. Summarizing the main diagnostic criteria, Woolfolk and Allen (2011) write that CFS is “characterized by unexplained fatigue, lasting at least 6 months, that causes substantial reductions in activities” (p. 352). Additionally, at least “four of the following symptoms must have co-occurred”: “significant memory impairment or concentration difficulties, sore throat, tender lymph nodes, muscle pain, joint pain, headache, nonrestorative sleep, and postexertional fatigue” (Woolfolk & Allen, 2011, p. 352). Michael Sharpe and Patrick O’Malley (2019) point out that, “in clinical practice,” patients who “have received a diagnosis of CFS” may also “meet [the] criteria for somatic symptom disorder as defined in DSM-5” (p. 714; see also American Psychiatric Association, 2013, pp. 309-315). However, opinions differ when it comes to treatment options: Sharpe and O’Malley (2019, pp. 727-729) list several options for pharmacological treatments and graded exercise therapy, while also discussing the benefits of cognitive behavioral therapy.

Whether CFS is a medical or a psychological/psychiatric diagnosis has become a moot point in the debate on the illness (Sharpe & O’Malley, 2019, p. 710). Charting the discussion in his book *Making Sense of Illness: Science, Society and Disease*, Robert A. Aronowitz (1998) observes that the dispute is not only one between medical and psychological/psychiatric professionals, but also between health professionals and patients. Patients have reported feeling dismissed by skeptical doctors who stick to a somatic approach and reduce the reported symptoms to the result of somatization (with the potential interpretation by others that the illness is “all in the mind”). At the same time, however, some health professionals fear that a formal acknowledgment of CFS will subvert medical authority and will result in misuse of the “sick role” (Aronowitz, 1998, p. 35). Due to the increasing influence of the biopsychosocial model in medical sciences, holistic approaches to chronic illnesses—those that take into account somatic, social, and psychological factors—may have become more popular over the last decades, although the discussion on CFS has continued unabated (Hawkes, 2011). The same questions continually arise (van Geelen, 2010): Is it a “real” illness? Is it of a somatic or a psychogenetic nature? Which treatments and/or interventions will prove to be the most effective—the pharmacological or the psychotherapeutic?

It is obvious that, as patients, Skloot, Carlson, and Rehmeyer struggle with these questions themselves, yet they offer readers more than merely an account of that struggle: They also offer answers. For example, they strongly emphasize the somatic nature of their illness and criticize those medical professionals who refuse to acknowledge the somatic reality of CFS or, even worse, who suggest that their condition is the result of a process of somatization. Skloot (1996) insists on a unknown “virus” as the cause of his illness (p. xiii), criticizing “medical practitioners” for their technocratic attitude (“if they can’t find it with machines, it doesn’t exist”) and for the fact that “the only thing [they] seemed not to be doing was listening to me” (pp. 10-13). Carlson (2004) claims that, at times, he “hates” the name of his illness, “because a majority of the medical community has

determined that CFS is solely the mass fabrication of hypochondriacs and malingerers who've been influenced by an aggressive media" (p. iii). "Being sick sucked," Rehmeyer (2017) writes in a similar vein, "but being told it was my own fault because I was psychologically fucked up and that my disease wasn't worth studying was enraging" (p. 120). In other words, besides personal accounts of illness, these memoirs also offer explicit reflections on a heated healthcare debate.

Indeed, the memoirs themselves have become acknowledged contributions to that debate. Setting aside the question of the medical or psychological explanations for the illness (which, remarkably, is hardly touched upon in the reception of these works), the response to these publications has been strongly affirmative. Despite a small number of critical readings, the memoirs are generally characterized as important sources of knowledge concerning the subjective and practical dimensions of CFS. Fellow patients and non-diagnosed lay readers praise them, describing the works as informative, insightful, inspirational, and helpful (see, for instance, Amazon, 2019; Carlson, 2019; Milner, 2011; Parker, 2017). One reader describes Skloot's memoir as "a good book to start the healing process" (Amazon, 2019); Rehmeyer's book is praised as "relevant and important reading for those wishing to understand more about ME, CFS" (GoodReads, 2019); and one fellow patient observes that Carlson has "caught the true essence of what this disease feels like" (Carlson, 2019).

Praise for the memoirs—especially their value as resources—is not limited to lay readers; they are also referenced in medical or scholarly literature on CFS. In her book *Illness and the Limits of Expression*, published as part of the University of Michigan Press's Literature and Medicine series, Kathlyn Conway (2007) reads Skloot's memoir as a source of information on "the experience of disembodiment" that illness can precipitate (p. 48); Carlson's book is included in the "resource list" of the New Jersey Chronic Fatigue Syndrome Association (2010); and Skloot's memoir is again referenced as a valuable resource on CFS in *Willard & Spackman's Occupational Therapy* (Vaughn, 2014, p. 1134).

Thus, it seems safe to conclude that these memoirs have come to function as sources of insight for lay readers and as credible evocations of patient experiences for medical professionals. However, in light of the contested epistemological value of illness narratives as sketched in the previous section, this raises a number of intriguing questions. To what extent can these specific memoirs be considered reliable representations of experiencing symptoms of CFS? What is their relation to the narrative dimension of the actual experiences of patients? Additionally, how do their formal, literary qualities contribute to the insights they produce? In the following section, I will attempt to answer these questions by analyzing the three memoirs in more detail, and specifically in light of medical sociological and psychological insights into the narrative dimensions of CFS.

AUTOPATHOGRAPHICAL WRITING AND THE NARRATIVE DIMENSIONS OF CFS

As shown, the memoirs of Skloot, Carlson, and Rehmeyer are generally considered to provide effective insights into their experience of being confronted with CFS. To assess their potential, as well as to reveal their limitations as sources of knowledge on the illness experience, I will approach them from two perspectives. First, I present a "medical" reading of the works. Here, "medical" is not meant to imply that the reading is a "textualized" version of a medical screening of a patient-annex-author; rather, I approach the memoirs as a social scientist with an interest in the medical domain would—as reports on what individuals say, do and experience in a medical context. This is achieved by contextualizing the memoirists' experiences within the body of extant medical sociological and psychological/psychiatric literature on CFS. My second reading acknowledges the memoirs as literary writings, namely, as aesthetic constructions that evoke experiential aspects of living with an unexplained chronic illness.

A MEDICAL READING: NARRATIVES OF CFS

Qualitative medical research based on patient interviews or focus groups has produced important insights into the narrative dimensions of CFS. Several studies have, for instance, shown that patients experience the illness as a “biographical disruption”: Suddenly, they find themselves confronted with unsettling limitations in their personal, social, and professional life, often resulting in a sense of identity loss. Patients feel alienated from their old, “healthy” self and experience their new self as a strange, second “I” (Asbring, 2001, p. 315).

The contested character of the diagnosis of CFS itself poses an additional problem for patients. Research indicates that the “diagnosability”—whether the illness can be diagnosed or not—plays an important role in the illness experience (Clarke & James, 2003, p. 1393). Patients experience a refusal to accept CFS as an acceptable diagnosis and/or a real illness as delegitimizing, adding considerably to their suffering (Larun & Malterud, 2007, p. 20; Ware, 1992, p. 347). Also notable is the way in which doubt expressed by others over whether their condition is “real” or not often strengthens their belief that there *is* an underlying somatic cause: According to a meta-review, “[patients] emphasize that their condition is *definitely not* a psychosomatic disorder” (Larun & Malterud, 2007, p. 24, emphasis in original; see also Horton-Salway, 2001, p. 255).

Given the chronic nature of CFS, the contested status of its diagnosis, and its unpromising prognosis, it is hardly surprising that the chaos narrative figures predominantly in the experiences of patients. However, this is not the only narrative voice shaping patients’ stories: Lisa Whitehead (2006) describes how CFS patients pass through different narrative stages. The first can be described as one of restitution: Patients initially assume that they simply have the flu, a viral infection, or some other somatically explainable ailment, for which they expect to find effective treatment. When all diagnostic attempts fail, the chaos narrative takes over. During this stage, patients remain in a state of uncertainty, feeling unheard or even dismissed by doctors and medical specialists. For some time, it was not uncommon that the diagnosis of CFS, when it was finally reached, was initiated by pa-

tients themselves after “educating” their medical practitioners with the help of knowledge they had acquired of their own accord.³ Subsequently, the restitution narrative returns: Now that their illness has a name, patients try out (sometimes multiple) new treatments, including alternative medicine, therapies, and diets (Whitehead, 2006, pp. 2240-2244). The final stage tends to be modeled on the quest narrative. Although patients feel neither “better” nor recovered, they come to accept and acknowledge that they have been transformed by the illness: They find that they have become better at establishing priorities and putting life in perspective; they have learned to take their time with themselves and others; and they have acquired new insights, for example the importance of good health, a loving family, or the social impact and cultural dimensions of being ill. Patients speak of a “new” self that they have learned to accept and appreciate, at times even preferring it over their “old” self (Clarke & James, 2003, p. 1391-1392).

When read in light of these medical findings, the memoirs of Skloot, Carlson, and Rehmeyer appear to be “classic” case histories. The narrative plot of all three texts initially unfolds according to the different stages that make up the established illness narrative of CFS. After falling ill, all assume they merely have the flu or a virus infection from which they will recover (Carlson, 2004, p. 27; Rehmeyer, 2017, p. 16; Skloot, 1996, p. xiii). Thus, initially, the narrative voice of restitution dominates their stories and accordingly, the memoirists take traditional measures in the hope of a quick recovery. “Surely,” as Rehmeyer (2017) recounts, “my body would recover on its own” (p. 18). Their malaise, however, continues, and after several months it becomes clear that they are not simply dealing with “a flu to the fifth power” (Skloot, 1996, p. 9). At this point, the chaos narrative sets in and the authors recount long series of doctor’s appointments, tests, and treatment strategies, all to no avail. Among other treatments, Carlson (2004) tries injections with porcine liver extract, drinking Chinese herbal teas, and a variety of nutritional dietary supplements. In his attempts to take control over the “chaos of my illness,” Skloot (1996, p. 87) takes part in a clinical field trial of Ampligen (rintatolimod) and even travels

to Europe to visit a spiritual medium. Rehmeyer (2017), too, combines visits to different medical specialists with appointments with a psychic.

The formal diagnosis of CFS, once finally achieved, marks an important turning point in the memoirs: The diagnosis gives a name to their illness and provides them with a recognizable etiology. As Skloot (1996) recounts: “Bad as the diagnosis was—a disease that could neither be treated nor cured—I wept with relief at having a name for it” (p. 12). The diagnosis also comes with knowledge about potential causes, an explanation for symptoms, and (the promise of) treatment strategies. As such, it can be said to function as what has been described as a “hyponarrative” (see Dings & Glass, 2020): the diagnosis offers a supra-personal, context-insensitive narrative format that invites a strong identification with the suggested symptoms and a bracketing of more personal and context-specific aspects of the illness. This is illustrated by the fact that in all of the memoirs under consideration, although the etiologies put forward by the authors differ—Skloot (1996, p. 45) points to a viral cause, Carlson (2004) claims CFS is an immune system disorder, and Rehmeyer (2017, p. 127) refers to the dangers of “toxic mold” or mycotoxins—the diagnosis offers the prospect of a return to a straight-forward restitution narrative. Once their illness had been classified, they again set out to find “the” cure.

This second restitution narrative, however, is soon replaced by yet another narrative voice. In this respect, the structure of the memoirs further aligns with the illness narratives of CFS patients. Once the authors come to realize that a clear-cut treatment option is not available to them after all, and once they accept that their condition is chronic, they begin to arrive at new, unexpected, and valued insights. Thus, the memoirs take on the form of a quest narrative. This is implicitly acknowledged by the repeated use of the metaphor of illness as a journey—an image that suggests an intentional movement toward a specific destination. Invoking Susan Sontag’s (1978) often-cited allegory of illness as a migration from the “kingdom of the well” to the “kingdom of the sick” (p. 3), Skloot (1996) structures his experience of his illness as a journey “into darkness” followed by a

“comeback” (p. 1, p. 160). The title of Carlson’s memoir invokes the famous musical *The Wizard of Oz* (Victor Fleming, 1939), in which the character Dorothy magically travels from her hometown in Kansas to the fictional Emerald City and back (p. 114). Finally, the metaphor of the journey is also implied by the word “odyssey” in the subtitle of Rehmeyer’s book. Although the insights gained by the authors on their journeys vary—from a new appreciation of the precious nature of time (Skloot), the beauty of nature (Carlson), to the importance of appreciating the present moment (Rehmeyer)—all of the authors report some form of personal “growth” (Carlson, 2004, p. 155; Rehmeyer, 2017, p. 307; Skloot, 1996, p. xiv).

Not only does the overall composition of the memoirs mirror the narrative development reported by CFS patients; other aspects of the illness experience also find a voice in these works. Just like their fellow patients, the authors describe the onset of their illness as a biographical “disruption.” Rehmeyer (2017) describes her illness experience as a type of “death” and observes that “the life I had lived was over” (p. xi); Skloot (1996) recounts how, during his illness, “the banks of my old self eroded” (p. xiv); and Carlson (2004), finally, notes that “being sick was my story, sad to say, my new identity” (p. 47). A final element that characterizes the memoirs as prototypical accounts of the narrative of CFS is the authors’ adamant refusal of any suggestion that their illness may be psychogenetic, let alone imagined. Rehmeyer (2017) notes that any suggestion that CFS might be “a brain problem” is, in her eyes, “wrong, offensive, and damaging” (p. 93). In passing, Skloot (1996) paraphrases his interpretation of the potential diagnosis “somatization disorder” as “it was all in my head” (p. 9). Similarly, Carlson (2004) understands psychosomatic approaches of his illness as profoundly dismissive: In his opinion, terms like “functional somatic syndromes” are “medical-speak for bullshit” (p. 111).

Thus, when one reads these memoirs from a medical perspective, it becomes apparent that these accounts bear many similarities to the narrative patterns reported by fellow patients. Readers of these memoirs become witness to the biographical disruption experienced by the illness; they are led

through the successive narrative stages (restitution, chaos, back to restitution, and, finally, quest) that characterize the illness experience; and they are offered an insider's perspective on the distrust and lack of understanding that CFS patients have to face, as well as on their resistance to psychosomatic, "metaphorical" interpretations of their symptoms. In light of these findings, it is tempting to conclude that illness memoirs indeed offer readers insights into the subjective experience of illness.

Yet "medical" or "diagnostic" readings, as presented in this section, have important limitations: They are, in fact, strictly mimetic interpretations of the memoirs—readings that approach these autopathographical writings as straightforward representations, glossing over their distinctly literary dimensions. Yet if one acknowledges these dimensions, as will be the case in the reading presented in the next section, it becomes clear that it is precisely this literary character that gives rise to questions about the status of illness memoirs as exemplary sources of information on the nature and experience of being confronted with CFS.

A LITERARY READING: CFS AS A NARRATIVE ENIGMA

The three memoirs differ in an important respect from the illness narratives described by medical researchers: They are autopathographies—that is, retrospective accounts of an illness experience put to paper by authors with the (potential) utilization of all the narratological, rhetorical, and stylistic devices at their disposal. Approaching these works as autopathographies quickly reveals that they are ambiguous aesthetic constructions that remain open to multiple interpretations. At times, these interpretations diverge remarkably, to the point where they can actually contradict one another.

For example, on closer inspection, it appears that the narratological composition of the memoirs points to alternative etiologies of the authors' illness. As has become clear, all of the memoirists emphasize the somatic nature of the ailment and resist attempts to understand their illness in psychosomatic terms. It is remarkable, therefore, that the authors at times draw attention to the possibility that their illness may *also* have emotional or psychological causes. For example, in the

preface to his memoir, Carlson (2004) announces somewhat enigmatically that "what happened to me was a direct result of who I was, socially, culturally, politically, and emotionally" (p. iv). Likewise, Skloot (1996) mentions in passing his reluctance to begin work on a "novel [he] needed to write"—"a novel about [his] childhood, about abuse" (p. 102). Rehmeyer (2017) is very open about the psychological dimensions of her experiences. She reflects on (the influence of) her strict religious upbringing, her marriage to a husband with bipolar disorder, and her difficult relationship with her parents—an abusive mother (who died early) and an absent father. However, Rehmeyer's memoir ultimately cites her discovery of toxic molds as a key factor in the development of her illness, her account also preferring a medical over a psychological explanation.

To be clear, I do not want to suggest that the complaints from which these authors suffer may be psychogenic in nature, as doing so would be both reductive and unethical (Furst, 2012, p. 53). Rather, I want to emphasize that Skloot, Carlson, and Rehmeyer, in their role as implied authors shaping their stories, foreground the somatic dimension of their illness history and downplay psychological dimensions. As such psychological factors are nonetheless referenced, however, this narrative intervention results in a form of "off-kilter narration"—a type of narration that goes "awry," from a rhetorical perspective, as attentive readers, unable to take the narration at face value, find themselves standing at some distance from what the implied author is stating (Phelan, 2011). In his work on the rhetorical dimensions of narrative, James Phelan (2005) proposes a taxonomy of different kinds of narrative unreliability that is useful in this context: with regard to the etiological aspects of their illness narratives, the authors of these CFS memoirs can be argued to be either "underreporting"—telling their readers less than they know—or "underreading"—offering their readers, perhaps unwittingly, an incomplete interpretation of their experiences (Phelan, 2005, p. 52). While it is the authors' privilege to narrate their experiences in a selective and subjective manner, this type of "off-kilter narration" does have important consequences for the status of these memoirs as

sources of knowledge. If the authors' accounts of their experiences are indeed selective, then one can no longer claim that autopathographical writing lends a voice to a "self-in-crisis" thrown upon its own bodily reality, as Hawkins (1999, p. 17) suggested, for in that case, the narrators are revealed as presenting narrative "versions" of themselves to their readers. An interpretive indeterminacy begins to manifest itself here, structurally undermining the reliability of the memoirs: Which aspects of the illness experience are included in the authors' accounts and which are excluded? How does this downplaying of psychological factors relate to the authors' insistence that their illness is of a somatic nature? Thus, when asking if CFS is a medical or a psychological issue, the memoirs are revealed to be indeterminate sources of knowledge.

On other occasions, further ambiguities are introduced by the authorial use of stylistic figures that frame medical explanations of the illness in terms of semiotic or symbolic explanations. At one point, Rehmeyer (2017) considers that her body's reaction to toxic mold could also be understood as a psychological response to traumatic experiences: "Mold might be the trigger," she writes, "like a car backfire that sends a veteran flying to the ground" (p. 260). This might seem like a simple analogy, but the comparison introduces a profoundly different explanatory framework: Rather than a *physical* relation between cause (toxic mold) of effect (illness), the simile suggests a *semiotic* relation: The mold, similar to the backfiring car, *signifies* something by association or convention. A similar symbolic reading is offered by Skloot (1996), who admits that, despite all the medical proof of the somatic nature of his illness, "it remains tempting to see [CFS] as somehow symbolic: Our world at the millennium is exhausting. Or it is a hostile place that defeats one's defenses. . . . Or pushing as hard as most Americans do, we court collapse" (p. 122). Here, the illness is presented as a *pars pro toto* for a larger cultural or societal ailment. Dismissing these uses of imagery as merely stylistic choices would be to deny their epistemological effect: They introduce an extension in meaning that semioticians label as metonymical displacement or "skidding" (Barthes, 1998, pp. 92-93; Silverman, 1984, p. 256), as a result of which

not only physiological, but also social, cultural, and contextual factors come into play as possible causes of illness. What this process of skidding, once identified by the reader, reveals, is that (lay) theories about relations between individual and collective, mind and body, and illness and society, are ideologically charged (Neckel, Schaffner, & Wagner, 2017): the conventional and political nature of these relations are presented as universal and self-evident. The ideological relation between individual, bodily fatigue and cultural or societal exhaustion, for instance, is well-researched by scholars of the history of ideas (Rabinbach, 1990; Neckel et al., 2017).

A final literary device that I want to single out as adding to the indeterminacy of the memoirists' accounts is the rhetorical figure of the *martyria*, or the appeal to personal experiences (Lanham, 1991, pp. 97-98). Intriguingly, all authors at some point qualify their claims about CFS by pointing out that the validity of their statements is limited to their personal situations. Looking back on the effects of his coping strategies, Skloot (1996) concludes that "for each person, surely, the details will vary, the untouched places will be different" (p. 159), whereas Carlson (2004) seems to agree when he writes that "recovery" can be "a singular and personal affair" at times (p. 132). Remarkably, Rehmeyer (2017), who claimed to bring "scientific authority" to the story of CFS, also notes that her "observations" on CFS are "personal" and that "my experience obviously doesn't establish that ME/CFS as a whole is caused by mold or related contaminants, and I strongly doubt that's true" (p. 304). Although the *martyria* is conventionally invoked to confirm a previous statement and persuade the listener, in these cases the opposite is true, as the figure questions the validity of what has been said. This, too, demonstrates how the literary aspects of the memoirs invite readers to put the works' epistemological claims in a critical perspective.

Thus, reading the memoirs of Skloot, Carlson, and Rehmeyer with a sensitivity toward their "formal organization, rhetorical structure and thematic content," as Woods (2011, p. 75) advised, brings to the fore how the narratological, rhetorical, and stylistic aspects of their accounts under-

mine their epistemological value. An examination of their composition draws attention to potential factors of influence glossed over by the authors: Rhetorical figures subvert the explanations offered and metaphorical phrases lead to semantic shifts that open up the accounts for alternative, even contradictory interpretations. As a result, the epistemological function of these memoirs has to be re-evaluated: As sources of information on CFS, they are structurally indeterminate.

CONCLUSION: FROM NARRATIVES OF INDETERMINACY TO THE ART OF UNCERTAINTY

The double reading of three CFS memoirs presented in this contribution has aimed to demonstrate the two faces of autopathographical writing. From one perspective, these texts reveal a remarkable similarity with the illness narrative reported by patients in medical interviews or focus groups. They describe the biographical disruptions experienced by patients, as they find themselves forced to come to terms with their new identities. The memoirs evoke the different narrative stages that characterize patients' stories and the authors emphasize the somatic nature of their condition, resisting psychosomatic explanations. That these memoirs have been read as exemplary accounts of CFS, therefore, is quite understandable. Yet from another perspective—one that approaches these memoirs in their simultaneous meaning as literary writings—the epistemological function of these illness accounts is revealed to be indeterminable. Insights into the illness experience are selectively presented, questioned, or troubled by narrative, rhetorical, and metaphorical ambiguities.

These memoirs demonstrate the complexity of autopathographies as sources of knowledge. It has become clear that the biographical crisis experienced by the “sick self” does *not* result in a stripping away of all “fictions, metaphors and versions of self,” as suggested by Hawkins (1999), nor does it offer readers guaranteed access to the “pragmatic reality and experiential unity of the autobiographical self” (p. 17). Rather, autopathographical writings should be considered as a type of “personal self-shaping . . . *within* specific liter-

ary laws,” as Radden and Varga (2013, p. 100; emphasis in original) argued. Imagery, plot, and genre bring with them a set of literary conventions and semantic implications that shape the construction of the autopathographical self. At the same time, however, the double reading offered above qualifies Radden and Varga's (2013, p. 100) position that autopathographies reveal more about literary discourse on being ill than they do about the concrete, raw experience of illness itself. After all, the memoirs do align with what is known about the self-narratives of CFS patients.

The first assumption put forward in the introduction to this article, therefore, can be confirmed: Autopathographical texts have a distinct value as, unlike medical case histories, they can grant readers access to subjective aspects of being ill. The second assumption—the argument that the insights offered by illness memoirs are problematic and even unreliable as a result of the literary character of autopathographies—needs to be qualified. It has become clear that the epistemological status of memoirs may be indeterminate, but this is not to dismiss them as valuable sources of knowledge altogether.

In fact, an important insight offered by the memoirs is that it is precisely this epistemological indeterminacy that is inherent in experiences of CFS. Indeed, a striking element of these memoirs is that they are riddled with open questions, conundrums, and situations marked by ambiguity. For example, Carlson's (2004) memoir states: “The doctor didn't know what it was or what to do” (p. 30); “It's one thing to be really sick, but what do you do when someone of authority says it ain't true?” (p. 51); and “We all search for the words to explain it” (p. 150). Looking back on his experiences, Skloot (1996) concludes: “How did I get sick? After years of telling my story to doctors and friends and fellow patients, after going over it endlessly, I still have questions” (p. 56); and “For all that I have come to know, it seems to me now that the mysteries only grow deeper” (p. 121). Finally, Rehmeyer (2017) observes that the mystery of her illness is such that “it felt as though [it] might as well have been controlled by the Greek gods, creatures more irrational and capricious than the human mind can comprehend” (p. 37).

In other words, the stories that these authors have to offer are not only *indeterminate* narratives, but also narratives of *indeterminacy*.

These acknowledgements of the structural uncertainties that the authors face illustrate an important dimension of the phenomenon of CFS, namely, that indeterminacy is an essential part of the illness experience (Cooper, 1997). Furst (2003) touches upon this dimension when she notes that it is this interpretive openness of psychosomatic phenomena that makes them specifically suitable to literary interventions: “Precisely this openness to multilayered interpretation and, above all, to metaphoricality”—that is, figurative, as opposed to strictly medically-objective, language—“make psychosomatic disorders an inviting terrain for reading from a literary angle” (p. x). The indeterminacy of these memoirs, in other words, effectively evokes an illness experience that the authors explicitly describe as “mysterious” (Skloot, 1996, p. 74); “unsettlingly ambiguous” (Rehmeier, 2017, p. 148); and even “invisible” (Carlson, 2004, p. 93). In her fitting conclusion, which might well serve as a summary of the narratives of CFS altogether, Rehmeier (2017) notes that “without a known explanation, the illness felt a bit like Schrodinger’s cat: neither dead or alive, neither physical nor psychological, and yet rich with possibility” (p. 51). Thus, it can be argued that it is the literary nature of autopathographical writing that captures an essential quality of experiencing symptoms of CFS: An unequivocal, clear-cut explanation is simply not yet available. This argument does not apply exclusively to the narrative dimensions of CFS, of course: the indeterminacy of autopathography, in fact, invites us to reflect on the narrative ambiguity, existential uncertainty, and the interpretive crises that characterize illness in its myriad forms (Mishel & Clayton, 2008).

It is this precisely this quality of illness memoirs, I would like to suggest, that could constitute an important, but rather different, value in a health-care context. Given that, epistemologically speaking, the insights offered by these narratives cannot be taken at face value, there are distinct limits to their use as therapeutic, (psycho)educational or self-management resources. As narratives of indeterminacy, however, they present their read-

ers with experiences of profound uncertainty and different ways to manage these experiences—be it in the form of denial or illness reification, or through self-reflexive acceptance of a state of continual indeterminacy. Here, a productive connection could be made with Merle H. Mishel’s (1990) work on “uncertainty in illness theory,” which aims to explain “how patients cognitively process illness-related stimuli as well as how they structure meaning of those events” (p. 257; see also Mishel, 1999). The processing of the uncertainty that surrounds a life-threatening of chronic condition is understood by Mishel as a form of “appraisal” that evaluates the uncertainty as a danger or an opportunity; as such, Mishel (1990) proposes, “uncertainty may be a condition under which a person can make a transition during illness from one perspective of life to a new, higher order, a more complex orientation towards life” (p. 260), which may also effect well-being and perceived quality of life (Padilla, Mishel & Grant, 1992). Linking my argument to this line of reasoning, I propose that the illness memoirs analyzed in this contribution can offer readers exercises in the appraisal of uncertainty—that is, they can stimulate the reader’s attentiveness to indeterminate stimuli, both on a narrative and a medical level, and to the effects of the strategies to manage them. Properly contextualized by both medical professionals and literary studies scholars, these memoirs of illness could thus function as self-help resources for uncertainty appraisal.

According to scholars such as Arabella Simpkin and Richard Schwartzstein (2016), greater attentiveness to uncertainty should even be regarded as “the next medical revolution”. With technological innovations, the rise of algorithms, and the increasing insight in the multifaceted complexity of illness, they argue, there is a clear need in the medical system to shift to “questions that focus on ‘how’ and ‘why’, not ‘what’—stimulating discussions that embrace the gray-scale aspects of human health and illness, aspects that cannot be neatly categorized” (Simpkin & Schwartzstein, 2016, p. 1714). “It is therefore critical,” Simpkin and Schwartzstein (2016, p. 1714) claim, “that we focus on thriving in this [gray-scale] space and changing our professional culture to allow

for uncertainty”. It is to this new medical “art of uncertainty” that an attentive reading of illness memoirs, with a sensitivity toward their literary qualities, can contribute.

NOTES

1. My analysis builds upon, and revisits, our analysis of narratives of chronic fatigue syndrome as published in Franssen and Van Geelen (2018). I would like to thank Stefan van Geelen, as well as my research assistant Savanna Breitenfellner, without whom I could not have written this article.

2. There is an ongoing debate among both patients and health professionals about the name used to refer to the syndrome under discussion: some prefer CFS, others myalgic encephalomyelitis or ME; some claim that the former is a more recent term for the latter, others insist that these abbreviations refer to distinct illnesses. In this article, I will refer to the syndrome described by Skloot, Carlson, and Rehmeyer as CFS, simply because this appears to be the terminology preferred by the authors.

3. See Whitehead (2006): “All eight people in this group ‘forced’ the issue of a diagnosis of CFS/ME by presenting the GP with a self-made diagnosis supported by the evidence they had acquired to back these assertions, a process that took most several years” (p. 2242).

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