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Reopening the Dialogue Between Literary Theory and Medicine: Toward Further Understanding and Management of Patients' Self-Experience

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We wholeheartedly agree with Lindsey Grubbs (2016) that true interdisciplinarity in the humanities and sciences requires the acknowledgment of the unique value of the research traditions involved. Grubbs demonstrates that scientific claims about the effect of literature on brain connectivity or theory of mind models, when not properly embedded in literary theory, can turn out to be based on debatable assumptions and outdated categorical distinctions, to the extent that these claims become normative and difficult to uphold. Moreover, she insists that involvement of the humanities could make a distinct added contribution: They could deepen our insight into less common

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forms of self-experience, notably in autism. In this commentary, we expand Grubbs's claims and explore how literature and literary theory might aid to further not only the nonnormative understanding but also, specifically, the management of vulnerable patients' self-experience.

SELF-MANAGEMENT AND SELF-NARRATION: THE PROBLEM

The need for new approaches to understand and manage self-experience of chronically ill patients, whether in somatic medicine or psychiatry, is clear. Over the last years, there has been a growing interest in self-management strategies in (mental) health care (Siantz and Aranda 2014; Lorig and Holman 2003). These strategies urge patients to share knowledge and responsibilities with health professionals, and try to actively involve them in the management of their own care.

In practice, however, self-management mostly comes down to a form of disease management by the patients themselves. This seems insufficient, as such an approach does not acknowledge that altered self-experience, limited autonomy, disordered identity, and impaired agency are often core parts of vulnerable patients' self-experience (e.g., in pediatrics, psychiatry, geriatrics). In other words, often the self itself is at issue (Kyrios et al. 2015). For such patient groups, self-management should start from a management *of the self* (van Geelen 2014). Since this is presently not the case, it is understandable that existing self-management approaches are criticized for not explicating their conceptual foundations (Lorig and Holman 2003) and for utilizing too restrictive models of the self.

Narrative approaches in health care, inspired by insights from literary studies scholars, have been used for quite some time to gain a deeper understanding of patients' self-experience. They draw from a long tradition of a dialogue between medicine and literature, which ranges from Aristotle's notion of tragedies as psychophysically "cleansing" in his *Poetics*, via Schreber's firsthand report on schizophrenia in *Memoirs of My Nervous Illness* (Table 1, example 1), to the satirical investigation of ethical issues and the role of medical professionals in Bergman's *The House of God*. This tradition has lead to two dominant trends in the field of literature and medicine. Novels are used in health professionals' education, as they provide an understanding of the subjective viewpoint of patients, and theories on illness narratives and life writing are probed for their potential to supply patients with tools to manage their experience of disease.

Referring to insights from scholars such as Bakhtin and Ricoeur, for instance, many researchers and professionals now assume that self-experience is, to a considerable extent, a form of self-narration. They claim that life is experienced as an unfolding story: We expect certain stages, characters, and connections, discern themes, voices, and perspectives, and we think of ourselves as the (main) author of our life story. This self-narration occurs in interaction with social and cultural expectations (e.g.. "life as a

Table 1 Three examples of narrativity

Example 1: An illness narrative

"During my first months here the miracles on my eyes were performed by 'little men', very similar to those I mentioned when describing the miracle directed against my spinal cord. These 'little men' were one of the most remarkable and even to me most mysterious phenomena; but I have no doubt whatever in the objective reality of these happenings, as I saw these 'little men' innumerable times with my mind's eye and heard their voices. The remarkable thing about it was that souls or their single nerves could in certain conditions and for particular purposes assume the form of tiny human shapes (as mentioned earlier only of a few millimeters in size), and as such made mischief on all parts of my body, both inside and on the surface."

D. P. Schreber, *Memoires of My Nervous Illness*
Schreber's famous account of his psychiatric illness provides clear insight in the inner working of a delusional and disturbed mind. Nonetheless, the reader is never confused about whom the narrator is, and the memoires are united by a developing plot and presented with a clear beginning and end.

Example 2: Realism and naturalism

"Thérèse grew up under the fostering care of her aunt, sleeping in the same bed as Camille. She who had an iron constitution, received the treatment of a delicate child, partaking of the same medicine as her cousin, and kept in the warm air of the room occupied by the invalid. For hours she remained crouching over the fire, in thought, watching the flames before her, without lowering her eyelids. This obligatory life of a convalescent caused her to retire within herself."

É. Zola, *Thérèse Raquin*
Zola presents his main protagonist's life story and the genealogy of her melancholic personality as intimately intertwined with the stories of those close to her. The story is chronologically structured and presented in a coherent form.

Example 3: Fact, fiction or fantasy?

"Back here again. These pages are a mess. Stuck together with honey from all my tea making. Stuck together with blood. No idea what to make of those last few entries either. What's the difference, especially in differance, what's read what's left in what's left out what's invented what's remembered what's forgotten what's written what's found what's lost what's done?
What's not done?
What's the difference?"

M. Z. Danielewski, *House of Leaves*
Danielewski's character Johnny Truant, in this quote, cannot tell the difference between fact and fiction when rereading his own journal entries. The novel soon loses its coherence and, alongside the characters, the reader is confused by a polyphony of undecipherable voices and left guessing about where the novel begins and ends.

success story," "life as a struggle and dealing with obstacles, e.g., illness"), and one's story is therefore always intertwined with the stories of others. Additionally, the self is often understood as an ongoing dialogue between different "sub-selves" or self-positions (Hermans and Dimaggio 2004). Not only do we interact with others, there is also interaction with different versions of oneself (e.g., "I as healthy," "I as sick"). One's sense of wholeness, then, results from a continuous dialogue between such positions. In the context of medicine, narrative approaches have resulted in an understanding of the self that more fully acknowledges patients' subjectivity. Specifically, they have made us aware of certain conditions for a "healthy" organization of self-narratives: for example, the ability to move from one storyline to another, the development of a varied repertoire of "characters," the potential to enter into meaningful dialogue, and the establishment of overall coherence (Lumsden 2004).

NARRATIVITY AND NORMATIVITY IN UNDERSTANDING THE "ILL" SELF

Taking their cue from literary theory, then, narrative approaches underline the importance of general aspects of narrativity, such as thematical coherence, the "anchoring" of the story in reality, the role of dialogue, and plot development. In this way, literature has helped medicine, neuroscience and psychiatry to more fully understand and manage the "ill" human mind.

These notions of self-narration, however, may not be ideally suited to understand self-experience in the already-mentioned patient groups. The medical appreciation of narration, after all, seems to have focused on a somewhat narrow and normative definition of narrativity. The analogue between writing a story and constructing a self is a good starting point for an evaluation of the current state of affairs in the medical use of narrativity. On closer inspection, the "healthy" self, as described earlier, seems modeled on a very distinct kind of story: the 19th-century realist or naturalist novel. Zola's *Thérèse Raquin* (Table 1, example 2) may serve as an example. The novel describes, in a plausible manner, from birth to death, the life of the heroine Thérèse. The narrative complies with cultural templates (e.g., "'one's social and physical conditions determine one's life course"), and revolves around a dominant theme that lends coherence to the story: the clash between Thérèse's melancholic nature and the temperaments of the other characters. Insightful as this parallel may be, it raises a difficult question: Can such a specific, historically and culturally situated form of narrative, and the particular reading it demands, suffice as a general model for understanding the "ill" self?

This problem becomes particularly clear in specialities concerned with non-fully formed, disordered or deteriorating narratives. After all, the self-experience of—for example—patients with psychopathological conditions is often characterized by very specific and rather unique aspects of narrativity (Phillips 2004), such as incoherence and "fictionality." Yet these elements are rarely investigated for what they are, that is, essential components of stories. By systematically acknowledging the expertise of humanities approaches to literature and theoretical insights into narrativity, a more theoretically sound, nonnormative understanding of patients' self-experience can be developed, which could open up perspectives for innovative approaches of managing this self. After all, literary works from other cultures or historical eras offer very different possible models. Here, one can think of a highly creative novel like Danielewski's *House of Leaves* (Table 1, example 3), a fragmented collage of texts and voices, playing with different levels of reality, and blurring the boundaries between fact, fiction, and fantasy. Strange as such works may be, one cannot claim that they are not forms of narration, that they lack structure, or that they fail to provide us insight into the self. Quite the contrary: Literary theorists have argued that they grant us profound insights into the complexities of modern subjectivity (Timmer 2010).

LITERARY THEORY AND SELF-MANAGEMENT: FUTURE DIRECTIONS

Not only do literary works and literary theory offer us very different narrative experiences, they also invite us to rethink our traditional expectations of coherence and referentiality. In literary theory we find sophisticated insights that point out that neither incoherence nor coherence is an inherent trait of stories. Rather, these are seen as culturally conditioned experiences. Incoherence, theorists argue, can be seen as granting access—and to some extent even providing a temporary defense—to traumatic experiences (Caruth 1996). As such, it offers unique insights into self-experience. Others have claimed that fictionality is not a "failed" form of referentiality, but crucial for the opening up of "possible worlds" or the creation of hypothetical scenarios (Gallagher 2006). Figures such as Ricoeur and Deleuze have even argued that fiction is intrinsically part of any form of self-narration. Literary theory, then, can help us to move beyond narrow definitions of narrativity and toward a systematic understanding of (self-)narration in (mental) health care, in which incoherence and fictionality are not merely maladaptive symptoms, but also productive tools.

Grubbs rightfully encourages a reopening of the millennia-long conversation about fiction's impact on the mind, and aims at true interdisciplinarity in neuroscience, cognitive psychology, and literary theory. We believe that there would also be a good deal to be gained from reopening the dialogue between medicine and literary theory. First, a systematic analysis of narrativity will further the understanding of altered self-experience: After all, vulnerable patients will often struggle with crude and developing, incoherent, deteriorating or delusional self-narratives. Second, through such an approach, fragmented or fictitious self-narratives are not necessarily labeled as abnormal. Rather, they can be seen as starting points for successful self-management, as the creative aspect of fictionality might well be used to empower patients, and to

explore different self-narratives or hypothetical scenarios. Some of these possibilities are currently already explored, but so far, a unified framework for truly understanding and managing the self in medicine still seems missing. Only when self-management strategies have a thorough conceptual foundation—of which a systematic analysis of literature and narrativity can provide an important building-block—can they fully realize their promise of providing effective and cooperative (mental) health care, and truly enable a management of the self.

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