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*Living with diabetes – or dying trying.
A novel approach*

Abstract: The aim of this study was to analyse a novel in order to explore illness perceptions and self-management behaviour in persons with diabetes. Illness perceptions are usually assessed by psychometrically sound questionnaires, and increasingly via drawings of specific illnesses. In this paper, an additional method of assessing illness perceptions is explored, namely examining literary fiction. The Self-Regulation Model (SRM) is the theoretical framework to examine chronic illness perceptions. A novel about a young woman with diabetes, *Going to the sun* by James McManus (1996), is used for data-analysis. Within the novel all eight illness perception dimensions that are employed in a psychometric measure to test the SRM are identified; associations between illness perceptions and self-management are observed, in line with the SRM. This approach demonstrates the value of using novels in (health) psychology research and could beneficially be extended to other genres, i. e., poems, films, music, and paintings. Exploring patients' narratives seems a fruitful avenue to further research and clinical applications for gaining insight into and potentially intervening in chronic illness behaviour. Studying novels adds to our knowledge about patient narratives.

Self-management and quality of life (QOL) have acquired a solid status in medicine and health psychology, thanks in particular to health care providers like physicians,

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nurses, physiotherapists, psychologists and others, and the patients themselves who, in constructive collaboration with health care providers, developed adaptive self-management skills in managing complex illnesses.² It is precisely because of the complexity of the tasks required to manage diabetes, both type 1 and type 2, that patients and their health care providers developed areas such as how to assess self-management skills, involve partners of patients, and include sensitive topics such as sexuality or maladaptive coping.³ Review papers on self-management in diabetes attest to the positive effects of adapting constructively to the diagnosis, to the pharmacological management of the disease, and adequate self-management behaviour by the patients themselves to keep the illness under control.⁴

Self-managing an illness is a rapidly developing area of research and patient care. Empowering patients via self-management seems beneficial for patients, their partners, health care providers and society.⁵ This is supported by strong evidence.⁶ Self-management is the cornerstone in the management of diabetes due to the continuous need for self-monitoring of glucose, which is impacted by and impacts virtually all behaviour, such as eating, social interactions and physical activity. Therefore, diabetes self-management is part and parcel of high quality medical care.⁷

² For example, Stanton P. Newman, Liz Steed, Kathleen Mulligan (Eds.): *Chronic physical illness. Self-management and behavioural interventions*. Maidenhead 2009.

³ For a review see Frank J. Snoek, Timothy C. Skinner, Liz Steed: *Diabetes*. In: Newman, Steed, Mulligan: *Chronic physical illness* (note 2), pp. 169–188.

⁴ Joana L. Hudson, Christine Bundy, Peter A. Coventry, Chris Dickens: *Exploring the relationship between cognitive illness representations and poor emotional health and their combined association with diabetes self-care. A systematic review with meta-analysis*. In: *Journal of Psychosomatic Research* 76 (2014), pp. 265–274.

⁵ Delia Chiamonte: *Who's afraid of the empowered patient?* In: *Journal of the American Medical Association* 300 (2008), pp. 1393–1394.

⁶ For example, in cardiology, e.g., Elizabeth Broadbent, Chris J. Ellis, Janine Thomas, Greg Gamble, Keith J. Petrie: *Further development of an illness perception intervention for myocardial infarction patients. A randomized controlled trial*. In: *Journal of Psychosomatic Research* 67 (2009), pp. 17–23, and oncology, e.g., Jamie M. Stagl, Laura C. Bouchard, Suzanne C. Lechner, Bonnie B. Blomberg, Lisa M. Gudenkauf, Devika R. Jutagir, Stefan Glueck, Robert P. Derhagopian, Charles S. Carver, Michael H. Antoni: *Long-term psychological benefits of cognitive-behavioral stress management for women with breast cancer. 11-year follow-up of a randomized controlled trial*. In: *Cancer* 121 (2015), pp. 1873–1881.

⁷ Linda Haas, Melinda Maryniuk, Joni Beck, Carla E. Cox, Paulina Duker, Laura Edwards, Edwin B. Fisher, Lenita Hanson, Daniel Kent, Leslie Kolb, Sue McLaughlin, Eric Orzeck, John D. Piette, Andrew S. Rhinehart, Russell Rothman, Sara Sklaroff,

A theoretical model underlying these studies is the Self-Regulation Model (SRM).⁸ The model underlines how patients have ideas or representations (cognitions) of health threats, as well as emotional responses to health threats and (dys)functions. These cognitions and emotions may be “objectively incorrect” in that a person’s ideas may not be accurate but this approach begins with the patients’ perceptions, whatever they may be. Cognitive and emotional representations drive coping – for example adherence with medication or adjustment of daily activities, – and appraisal of its effects, including how the illness is incorporated into one’s life across social, sexual, financial and other dimensions. The cognitive and emotional representations of a health threat or an illness comprise illness perceptions. They drive coping behaviour, which in turn affects QOL. Research and clinical care in the area focus on patients with chronic somatic illness, for example cancer, rheumatoid arthritis and cardiovascular diseases.⁹

Illness perceptions have been assessed with questionnaires,¹⁰ drawings,¹¹ or by interview¹². Research has examined illness perceptions in patients with diabetes. A US study shows how adaptive illness perceptions are associated with adequate self-management in people living with diabetes.¹³ Fortenberry and colleagues studied illness perceptions in a longitudinal design in American adolescents with type 1

Donna Tomky, Donna Youssef: National standards for diabetes self-management education and support. In: *Diabetes Care* 37 (2014), pp. 144–153.

⁸ Howard Leventhal, Ian Brissette, Elaine A. Leventhal: The common-sense model of self-regulation of health and illness. In: Linda Cameron, Howard Leventhal (Eds.): *The self-regulation of health and illness behaviour*. London 2003, pp. 42–65.

⁹ For a systematic review of the topic see Elizabeth Broadbent, Carissa Wilkes, Heidi Koschwanez, John. Weinman, Sam Norton, Keith Petrie: A systematic review and meta-analysis of the Brief Illness Perception Questionnaire. In: *Psychology & Health* 30 (2015), pp. 1361–1385.

¹⁰ E.g., IPQ-R, Illness Perception Questionnaire Revised, see Rona Moss-Morris, John Weinman, Keith John Petrie, Rob Horne, Linda Diana Cameron, Deanna Buick: The Revised Illness Perception Questionnaire (IPQ-R). In: *Psychology and Health* 17 (2002), pp. 1–16.

¹¹ Elizabeth Broadbent, Keith J. Petrie, Chris J. Ellis, Janine Ying, Greg Gamble: A picture of health – myocardial infarction patients’ drawings of their hearts and subsequent disability. A longitudinal study. In: *Journal of Psychosomatic Research* 57 (2004), pp. 583–587.

¹² See www.uib.no/ipq for details (accessed 3/25/2017).

¹³ Joseph Thomas, Neeraj N. Iyer, William B. Collins: Associations between perceived chronic care quality, perceived patient centeredness, and illness representations among persons with diabetes. In: *Journal of Healthcare* 36 (2014), pp. 50–59.

diabetes.¹⁴ They found that illness perceptions tended to become more adaptive and instrumental in encouraging adequate self-management behaviours over the years. The results of the DIAMOS study, addressing cognitions and emotions, showed how cognitive behavioural interventions reduced diabetes distress and improved QOL.¹⁵

An innovative addition to the SRM pertains to the area of Medical Humanities, defined as “an interdisciplinary field of medicine which includes the humanities (literature, philosophy, ethics, history and religion), social science (anthropology, cultural studies, psychology, sociology), and the arts (literature, theater, film, and visual arts) and their application to medical education and practice”¹⁶. Various art genres can help understand how persons make sense of “stimuli, deviation from normal, health equilibrium” (the starting point of the SRM). Novels, poems, films, and music are available as rich sources for studying how people make sense of those stimuli, complaints, and illnesses.¹⁷ Great novels like *Cancer Ward* by Alexander Solzhenitsyn¹⁸ or *The Magic Mountain* by Thomas Mann, poems like *The surgeon at 2 a. m.* by Sylvia Plath, films like *The seventh seal* by Ingmar Bergman about the plague, and paintings like *65 roses* about cystic fibrosis¹⁹ are treasure troves of representations of various illnesses and the coping behaviours of those suffering from them. For diabetes, various examples in these art genres are available. A painting about diabetes is depicted in Figure 1, drawing on the metaphor of controlling one’s diabetes.

¹⁴ Katherine T. Fortenberry, Cynthia A. Berg, Pamela S. King, Tammy Stump, Jorie M. Butler, Phung K. Pham, Deborah J. Wiebe: Longitudinal trajectories of illness perceptions among adolescents with type 1 diabetes. In: *Journal of Pediatric Psychology* 39 (2014), pp. 687–696.

¹⁵ Norbert Hermanns, Andreas Schmitt, Annika Gahr, Christian Herder, Bettina Nowotny, Michael Roden, Christian Ohmann, Johannes Kruse, Thomas Haak, Bernhard Kulzer: The effect of a diabetes-specific cognitive behavioral treatment program (DIAMOS) for patients with diabetes and subclinical depression. Results of a randomized controlled trial. In: *Diabetes Care* 38 (2015), pp. 551–560.

¹⁶ Howard Brody: Defining the Medical Humanities. Three conceptions and three narratives. In: *Journal of Medical Humanities* 32 (2011), pp. 1–7; www.litmed.med.nyu.edu (accessed 3/25/2017).

¹⁷ Therese Jones, Delese Wear, Lester D. Friedman (Eds.): *Health Humanities Reader*. Rutgers, NJ 2014.

¹⁸ Aleksander I. Solzhenitsyn: *Cancer Ward*. London 1970.

¹⁹ www.65roses.org.au (accessed 3/25/2017).



Figure 1 Patient controlling diabetes, or:
diabetes controlling patient?²⁰

Films where living with diabetes is a more or less prominent theme are discussed in the paper “The cinema of control”²¹, with *Steel magnolias*²² as one example.

The Jonas Brothers put diabetes in music: they perform the song *A little bit longer*, where the lyrics contain illness perceptions about diabetes.

Got the news today doctor said I had to stay
A little bit longer and I'll be fine
When I thought it'd all been done
When I thought it'd all been said
A little bit longer and I'll be fine
But you don't know what you got until it's gone
And you don't know what it's like to feel so low
And every time you smile, you laugh, you glow
You don't even know, know, know
You don't even know

²⁰ See Google search with keywords “diabetes paintings control”, https://www.google.nl/search?q=diabetes+paintings+control&biw=1024&bih=746&tbm=isch&tbo=u&source=univ&sa=X&ei=C0IuVcvLL8z_aKW_gPgG&ved=0CCgQsAQ&dpr=1.25 (accessed 3/25/2017).

²¹ Kevin L. Ferguson: The cinema of control. On diabetic excess and illness in film. In: *Journal of Medical Humanities* 31 (2010), pp. 183–204.

²² *Steel magnolias*; USA 1987, Robert Harling.

All this time goes by, still no reason why
 A little bit longer and I'll be fine
 Waiting on a cure but none of them are sure
 A little bit longer and I'll be fine²³

The book *Diabetes in Medizin- und Kulturgeschichte* by Dietrich von Engelhardt beautifully reviews various art forms in their representation of diabetes.

Control appears to be a central notion about living with diabetes, represented in paintings, film and music. The aim of the current study was to analyse a novel on diabetes, paying particular attention to the protagonist's experiences, views, cognitions and emotions. We used the SRM as the overarching theoretical framework and sought to identify in the novel the eight dimensions that make up illness perceptions.

Method

The Novel

The novel *Going to the Sun*, 342 printed pages, was published in 1996 and is still available (Picador Publishers), with no translations yet in other languages.²⁴ *The New York Times'* review of the book is very positive.²⁵ Prior to *Going to the Sun*, James McManus published three other novels, a collection of stories and a volume of poems. Since then, he has published three works of non-fiction: a bestselling memoir, entitled *Positively Fifth Street. Murderers, Cheetahs, and Binion's World Series of Poker*²⁶, *Physical. An American Checkup*²⁷, and *Cowboys Full. The Story of Poker*²⁸. The second one

²³ https://www.google.nl/search?site=&source=hp&q=a+little+bit+longer+jonas+brothers+lyrics&oq=A+little+bit+longer+&gs_l=psy-ab.1.0.014.919.7372.0.8751.20.20.0.0.0.70.1121.20.20.0....0...1.1.64.psy-ab..0.20.1115...0i131k1.vuoPrZfH5qk (accessed 8/5/2017).

²⁴ James McManus: *Going to the Sun*. New York 1996.

²⁵ James Marcus: *North to Alaska*. In: *The New York Times* (2/18/1996).

²⁶ James McManus: *Positively Fifth Street. Murderers, Cheetahs, and Binion's World Series of Poker*. New York 2003.

²⁷ James McManus: *Physical. An American Checkup*. New York 2006.

²⁸ James McManus: *Cowboys Full. The Story of Poker*. New York 2009.

of these is a collection of essays on health, mortality, medical research and the US healthcare system.

Going to the Sun narrates in striking detail a young woman's struggle with chronic illness. The author's detailed knowledge of diabetes, and of what it is like to live with this chronic condition, can in part be explained by the fact that McManus' father was a diabetic, while his daughter Bridget, to whom the novel is dedicated, was diagnosed with diabetes at the age of 4; she was 21 when *Going to the Sun* was published.²⁹ Yet it is also McManus' literary imagination which enables him to enter into the perspective of a young woman suffering from chronic illness, and to engage empathetically with the protagonist's experiences as a woman more broadly. An example is when the protagonist, having checked in at a motel, covers the mirror in her room with her shirt before taking a shower, in case it might conceal "a cagey manager's custom designed, impossible-to-detect peephole"³⁰.

Below, we will examine in more detail how the novel represents the experience of diabetes, as well as how that representation can be linked to the novel's status as a work of literature – as prose fiction. Our aim in these paragraphs is to shed some light on the larger narrative into which McManus incorporates the issue of diabetes, and on the themes examined in the novel as a whole.

Throughout the novel, the narrative perspective is that of the protagonist, Penny Culligan, who speaks in the first person. In the novel's first, comparatively short section, Penny's boyfriend David is attacked by a bear during a camping trip in Alaska. Severely mutilated during the attack, David manages to communicate to Penny that he wishes to die. She grants his request by injecting "two hundred units of Regular insulin"³¹ into his body. At its outset, therefore, the novel poses the question of when physical suffering becomes unbearable, and at what point bodily malfunctioning destroys our very sense of self. David is dehumanized – made into a thing – both by his extreme injuries and by the medical attempts to keep him alive: "What I saw when I entered the room was a tape and gauze sculpture connected by cables and tubes to various monitors and stabilizing devices"³².

²⁹ John Blades: Close To Home. Elements From James McManus' Own Life Form The Emotional Core Of His New Novel. In: Chicago Tribune (5/27/1996). http://articles.chicagotribune.com/1996-05-27/features/9605270072_1_new-novel-penny-previous-books (accessed 3/25/2017).

³⁰ McManus: *Going to the Sun* (note 24), p. 67.

³¹ McManus: *Going to the Sun* (note 24), p. 40.

³² McManus: *Going to the Sun* (note 24), p. 31.

While the rest of the novel focuses more strongly on Penny's struggle with diabetes, the issue of coping with the long-term effects of chronic illness is juxtaposed, then, with the sudden, near-total destruction of David's body, and the question of (assisted) suicide as a response to unbearable physical suffering hovers over the novel as a whole. In the novel's first section, furthermore, insulin, a life-saving substance for Penny herself, serves as an instrument of death – a desired death, but a death nonetheless. In this way, the novel suggests that Penny's treatment itself may eventually become death-like. Indeed, she notes that her exasperation at the daily grind of self-medicating and self-monitoring is stronger than her fear of death:

I don't think I'm terribly afraid of dying, at least not much more than the next person. What I've never been able to tolerate is the hassle of feeling drowsy or sick half the time, of having to monitor every last Grapenut and minute of exercise and unit of insulin. It's the fucking inconvenience that gets me. I'd also like to make this official: I've done my time in hospitals, doctors' offices, and blood-test labs.³³

The bulk of the novel narrates the solitary bicycle trip from Chicago to Alaska which Penny undertakes seven years after the events in Alaska. Her motives in going on this trip are not entirely clear to herself (though a desire to break out of her PhD dissertation writer's block does play a role), and she in fact resists the idea that she has one overriding motivation: "I have dozens of theories about why I'm taking this trip, all about equally serviceable"³⁴. The novel's two mottos in fact form a suggestive commentary on this issue: the closing lines from Dante's *Divine Comedy*, in which Dante has a vision of divine love, and the opening lines of Samuel Beckett's poem *Sanies I*, in which the speaker cycles through the Irish countryside, much like Penny cycles through the American landscape in *Going to the Sun*. Taken together, the two mottos invite us to see Penny's trip as a metaphor for her life more broadly, and suggest that her trip may lead to a climactic, redemptive vision, just as Dante's journey in the *Divine Comedy*, which begins "Midway in the journey of our life"³⁵, culminates in his vision of the Holy Trinity. Yet Penny's PhD dissertation is on the Irish playwright, novelist and poet Samuel Beckett (1906–1989), and the many allusions to Beckett's work, especially his novels, hint at an alternative, more nihilistic ending. In the novel's last sentences, Penny casually quotes and reworks the famous

³³ McManus: *Going to the Sun* (note 24), p. 83.

³⁴ McManus: *Going to the Sun* (note 24), p. 73.

³⁵ Dante: *Divine Comedy*, *Inferno* 1.1.

closing words of Beckett’s novel *The Unnamable*: “You must go on, I can’t go on, I’ll go on. Or whatever. I’m going”³⁶. While Beckett’s unnamed, lonely narrator continues to speak his endless monologue, even as he is unable to go on, Penny announces that she is “going” rather than “going on”. Indeed, throughout her trip, she imagines various versions of her own death, with the following passage as a particularly striking example:

[T]he real trick is to somehow make [death] an act of pure joy. A big-time relief to be sure, but something more sublime or expansive than that: lightning out for another form of consciousness [.] (...) Maybe (...) turn into a tree. This was, after all, Dante’s clear-eyed idea of a suitable punishment, and it’s never struck me as a particularly infernal form of existence. I don’t think I’d mind spending my time as a spruce, with a couple of finches’ nests, say, in the forks of my branches; or maybe a paper-bark maple, with all of those magnificent six-pointed leaves turning amber and gold in the fall. I’d love to just stand near some river or ocean or lake, in the sun or the thunder, get rained on and snowed on.³⁷

McManus’ novel leaves undecided the precise nature of Penny’s eventual “going”, though there is a suggestion on the final pages that she is hurtling towards her death as she dashes down Logan Pass in Glacier National Park, Montana, loosening her grip on her bicycle’s brakes. She relishes the “giddy abandon”³⁸ which she feels at this moment, as well as a thrilling sense of danger: “I doubt my rear brakes could stop me right now”³⁹. While she has always been in medical danger, she is now experiencing a form of danger which she has deliberately chosen. Moreover, while she has always had to closely monitor her daily physical habits, she now deliberately, joyfully relinquishes control over her body. In his 1997 review of *Going to the Sun*, Steven Kellman rightly notes that “Penny envisions death as deliberate and decisive, a graphic contrast to the muddle of existence”⁴⁰.

It is not our intention to suggest that *Going to the Sun*, or any novel for that matter, offers unproblematic, “accurate” information on the real-life experience of chronic illness. It is, of course, true that McManus’ novel examines issues that do have a

³⁶ McManus: *Going to the Sun* (note 24), p. 342, italics in original.

³⁷ McManus: *Going to the Sun* (note 24), p. 85.

³⁸ McManus: *Going to the Sun* (note 24), p. 340.

³⁹ McManus: *Going to the Sun* (note 24), p. 340.

⁴⁰ Steven G. Kellman: Half in Love with Easeful Death. In: *Michigan Quarterly Review* 36 (1997). <https://quod.lib.umich.edu/cgi/t/text/textidx?cc=mqr;c=mqr;c=mqrarchive;idno=act2080.0036.322;g=mqrg;rgn=main;view=text;xc=1> (accessed 3/25/2017).

purchase on reality: diabetes is all too real, as is the struggle with chronic illness faced by many people in modern-day societies. In this sense, McManus' novel can be said to have a mimetic, life-like quality, as well as an autobiographical dimension, given the fact that the author's daughter was diagnosed with diabetes at the age of four, a subject which he also explores in his later novel *Physical. An American Checkup*. Yet it is important to emphasise that *Going to the Sun* offers a literary representation of illness perceptions. Using the medium of prose fiction, McManus enters sympathetically into the perspective of a young woman coping with chronic illness, incorporating her perceptions of illness into a larger narrative that addresses a cluster of interrelated themes. These include the experience of chronic versus acute illness; the relation that people, and especially women, have to their bodies, not just during illness; the impact of illness on one's professional ambitions; the impact of illness on sexuality; human attitudes towards death as well as (assisted) suicide; the ways in which we experience and respond to nature.

As was also noted above, the journey on which the protagonist embarks, which takes up most of this novel, is a literary trope with a long history that goes back to classical antiquity, while the road trip is an iconic American plot device. A full analysis of *Going to the Sun* would pay systematic attention to such aspects of its literary form, and is beyond the scope of this article. Our analysis focuses especially on the role of illness perceptions in MacManus' novel, and aims to demonstrate that there is a remarkable degree of correspondence between the protagonist's response to illness on the one hand and the categories employed in SRM on the other. This is not to say, of course, that the novel offers an accurate or "correct" representation of life with diabetes mellitus type 1, but rather that it forms a useful tool for engaging with the experiences and perceptions of someone who suffers from chronic illness. It is one of our contentions that reading a novel like *Going to the Sun* can help health-care professionals and medical students engage with the illness perceptions which they will inevitably encounter in their professional lives.

Indeed, fiction makes such engagement possible not because of its representational accuracy but precisely because of its literary qualities. *Going to the Sun* offers up for our sustained inspection the experience of chronic illness in a way that is rarely possible in real life, or with real-life accounts of illness. This is in large part because its author imagines in such detail the many ramifications of the protagonist's illness – its connections to a range of aspects of her life and sense of self, from her job to her sexuality. In this way, a novel like *Going to the Sun* makes it possible to

reflect on what the dimensions of illness perception identified in SRM models mean in concrete situations – in what ways chronic illness can impact an individual's daily life, for example, or how chronic illness affects the ways in which we experience our bodies. Moreover, because McManus' novel pits acute trauma – in the novel's first section, the protagonist's boyfriend is mutilated by a grizzly bear – against the protagonist's protracted struggle with diabetes, it invites readers to ponder the relation between the two. This is an effect of the novel's formal characteristics, which enable a mode of reflecting on illness perceptions rarely found outside the realm of fiction.

The author

The novel is written from the protagonist's perspective. The (male) author James McManus is a novelist and poet. He teaches writing and comparative literature at the School of the Art Institute of Chicago. It is unclear how he gained his impressive insider knowledge about living with diabetes, or why he chose to write a female main character. The novel received very favourable reviews, from respected sources.⁴¹

The analytic procedure

We identified quotes from the novel that matched the descriptions of the eight dimensions of illness perceptions. A large number of quotes were identified and these were coded into the dimensions in a relatively straightforward manner.

Results

All eight dimensions of the SRM were identified within the novel. Elements from these are outlined below, with quotes from the text.

⁴¹ For example Marcus: North to Alaska (note 25).

Consequences: the effects of diabetes on daily life

Protagonist Peggy appears to be very well informed about causes, consequences, and medical treatment of type 1 diabetes. The novel provides many illustrations of the consequences she perceives regarding the disease – and how she uses this knowledge to project in the future. For example:

they go on to describe how nearly every major organ gets ravaged. Since your kidneys no longer produce enough red blood cells, your bones get soft and you become anemic. Your neuromuscular system breaks down, and you lose your ability to concentrate. You get infections. You have strokes. You go blind. You spend most of your time in the hospital, and that's where you die. In the meantime, in order to "save" you, doctors will amputate things.⁴²

Here Peggy talks about a general "they", referring to medical professionals. In this way her knowledge about the course of diabetes comes from trained health professionals working in the field. Later in the novel Peggy uses this knowledge to explain how she feels about the possible consequences of the disease: "I obsess about eyes all the time."⁴³; "I'm going to die soon."⁴⁴; "... since it's slowly but efficiently slaughtering me."⁴⁵ Peggy knows about the damage diabetes does to eyes, kidneys, bones, neuromuscular systems, and more. In the course of her bicycle trip her anxieties about future consequences of her illness become more prominent, as the chosen quotes illustrate.

Timeline: perceived duration of the illness

Peggy was diagnosed with type 1 diabetes at a young age. She knows very well that diabetes is a chronic illness. Its timeline, therefore, is not acute but chronic. She reads about "breakthroughs" in the treatment of diabetes all the time, only to become cynical about yet new "breakthroughs" when she finds out they do not help her at all. Many patients with chronic illnesses tend to score this illness perception

⁴² McManus: *Going to the Sun* (note 24), p. 82.

⁴³ McManus: *Going to the Sun* (note 24), p. 130.

⁴⁴ McManus: *Going to the Sun* (note 24), p. 297.

⁴⁵ McManus: *Going to the Sun* (note 24), p. 342.

dimension towards the “acute” anchor point, only to learn the hard way that a chronic illness, by definition, will not disappear. For example, Peggy perceives the timeline of her disease as follows: “Twenty-nine months from now I might be strokebound in a wheelchair, blind, minus a few of my toes, shitting into a fitted diaper, drool slanting across my chin as I press some small steel button and call out for – what? What could I possibly want?”⁴⁶ She also is realistic (but simultaneously angry) about the chronic nature of her condition, and what this means for self-management:

Having to monitor my blood sugar levels twenty four hours a day every week, every year, every day, when other people’s pancreases did this work for them seemed more than a little inequitable. Requests that I do any further monitoring I considered as class-X offenses.⁴⁷

Here, it becomes clear how “real” patients combine various illness perceptions in one statement about their illness and its treatment.⁴⁸

Personal control: degree to which the patient perceives to be able to control the illness and its treatment her/himself

Most patients struggle very hard to keep control over their illness.⁴⁹ Peggy is no exception. She does her utmost to control her diabetes; she manages most of the time. Sometimes, however, she simply wants to let go. On the penultimate pages of the novel, she does let go – with fatal consequences. Personal control is instrumental in self-managing an illness such as diabetes. In the quotes below Peggy’s musings highlight the ways in which control was a key part of her life, from thinking about controlling her own death, to controlling the management and symptoms of the disease: “Another determining factor was my own plan to kill myself when my symptoms became too severe.”⁵⁰; “I’ve never felt leaner or stronger – more ‘in con-

⁴⁶ McManus: *Going to the Sun* (note 24), p. 65.

⁴⁷ McManus: *Going to the Sun* (note 24), p. 114.

⁴⁸ John C. Pickup, Melissa Ford Holloway, Kritika Samsi: Real-time continuous glucose monitoring in Type 1 diabetes. A qualitative framework analysis of patient narratives. In: *Diabetes Care* 38 (2015), pp. 544–550.

⁴⁹ Newman, Steed, Mulligan: *Chronic physical illness* (note 2).

⁵⁰ McManus: *Going to the Sun* (note 24), p. 41.

trol,' as the pancreatically challenged so like to put it."⁵¹; "In the meantime I'm using up x ergs of energy, y grams of glucose, together with an appropriate measure of insulin. Toot! It's perfect. Regular strenuous exercise actually increases my sensitivity to insulin, lets my muscles use it more efficiently. If I give myself the same doses every morning and evening, eat the same amount of grains, fruits, meats, and vegetables, then ride the same number of miles every day, I will in theory at least maintain my blood sugar levels pretty much in the range of a normal person, something I've never in my life been able to accomplish, outside the odd stint in a hospital."⁵²; "Because that's what this trip is about, after all: self-control."⁵³

Peggy admits that she is not in control of all things all of the time (in a similar way to most patients). She contrasts her experience of living with diabetes with "a normal human being", marking herself as outside this category due to her illness.

It's the f***** inconvenience that gets me. I'd like to make this official: I've done my time in hospitals, doctors' offices, and blood-test labs. I've sat on my last too-high examination table in a backless paper smock listening to very bad news from a preoccupied doctor, or getting lectured about the damage I've "let happen" by living like a normal human being.⁵⁴

Treatment control: degree to which the patient perceives medical treatment to be effective

In his *The wounded storyteller*, Frank distinguishes three types of illness narratives. The "restitution narrative": "Today I'm healthy, tomorrow I'm ill, the day after tomorrow I'll be healthy again". The "chaos narrative" pertains to stories patients tell themselves and their health care providers about how they are unable to make sense of causes, consequences, and coping with an illness. The "quest narrative" is about how patients somehow come to terms with their illness by attaching meaning to pain, loss, and death. Peggy is not optimistic about the degree of control that the medical management of her diabetes delivers, judging from her quotes in the novel.

⁵¹ McManus: *Going to the Sun* (note 24), p. 50, on her bicycling.

⁵² McManus: *Going to the Sun* (note 24), p. 61.

⁵³ McManus: *Going to the Sun* (note 24), p. 68, also about her bicycling trip.

⁵⁴ McManus: *Going to the Sun* (note 24), p. 50.

But no matter how fanatically I test, monitor, exercise, or weigh my meals down to the pictogram, it never becomes an exact science; it's more of a clandestine, Talmudic, repulsively insular twice-a-day ritual. Stress, menstruation, stray hormones, colds, grouchiness, or exhalation all affect your sugar levels in ways you can never predict. Even when doctors have you cathetered up to an insulin drip and are doling out hospital food, they can't hit it right on the money.⁵⁵

Peggy highlights not just the inadequacy of her own personal attempts of controlling her disease, but also the inadequacy of the medical profession with their more invasive technologies. This leads her to be pessimistic (perhaps accurately so) about the consequences for her health: "I have to accept the fact that I'm losing my health, though I never really had one to begin with. And I cannot accept this."⁵⁶

Identity: the symptoms and signs associated with the illness,
as perceived by the patient

Peggy is acutely perceptive and aware of her symptoms and bodily responses. She is vigilant about what her diabetes does to her body and mind. "If I started slurring my words or became stuporous (...), if I still ended up passing out (...)"⁵⁷; "The headaches I've been getting for the last several days are different from any I can remember. Not that the pain is much greater – it feels like it's deeper, closer to the center of my brain. (...) I'm going to die soon."⁵⁸ Peggy compares herself to a "normal" person to demonstrate how she perceives herself and her identity as being not a normal person: the disease marks her out continually as not-normal. This is essentially what the novel is about – her identity as a person with diabetes, rather than living life as a normal person.

⁵⁵ McManus: *Going to the Sun* (note 24), p. 75.

⁵⁶ McManus: *Going to the Sun* (note 24), p. 81.

⁵⁷ McManus: *Going to the Sun* (note 24), p. 19.

⁵⁸ McManus: *Going to the Sun* (note 24), p. 297.

Concern: degree to which the patient worries about the illness and its consequences

Persons with diabetes differ in the degree to which they worry about the condition. “Blissful ignorance” and “deadly catastrophizing” are the two anchors on this dimension.⁵⁹ Peggy, although strong and tenacious, in the end is extremely concerned about her diabetes. “You can’t clean your blood or turn food into energy properly. You poison yourself coming and going. And it keeps getting worse every day.”⁶⁰; “... what I do understand makes me worry incessantly, and worrying makes me destroy myself faster ...”⁶¹

Coherence: degree to which a person comprehends the nature of the illness and its treatment

Peggy comprehends very well what diabetes is and what the various symptoms and signs mean for her, and for any person with diabetes. She does not know answers to all her questions, though. “Why are the glomeruli inside my kidneys filtering my blood less efficiently? Why doesn’t my pancreas work? The answer is *Je ne sais pas*. Not exactly.”⁶²; “Through reading about it, through the unofficial network of diabetics anonymous, through osmosis – however it arrived in my brain, I finally started to actually process what was in store for me.”⁶³

Emotions: patient’s feelings associated with the illness and its treatment

Peggy experiences a wealth of emotions regarding her illness and its management: the use of terms such as “ruined” and “kill” in the first quote below attest to this. “I don’t want to let the thing that has ruined my life also kill me.”⁶⁴ Peggy also

⁵⁹ Pickup, Holloway, Samsi: Real-time continuous (note 48).

⁶⁰ McManus: *Going to the Sun* (note 24), p. 80.

⁶¹ McManus: *Going to the Sun* (note 24), p. 82.

⁶² McManus: *Going to the Sun* (note 24), p. 80.

⁶³ McManus: *Going to the Sun* (note 24), p. 120.

⁶⁴ McManus: *Going to the Sun* (note 24), p. 83.

describes negative emotions such as anger in relation to living with diabetes, but this is stronger still when she discusses how people implied there was a possibility of curing the disease, when she talks about experiencing “unfocused rage”: “That made me angry. No one had ever explicitly promised me I’d be cured by the time I was twenty, but my father had certainly given me to infer that (...) my response to this news was three years of unfocused rage.”⁶⁵

Discussion

A number of findings stand out. First, the various illness perceptions in the SRM are identifiable in *Going to the sun*, reinforcing the value of the model. Others have also studied how patients make sense, cognitively and emotionally, of symptoms and signs. Kleinman is one of the first researchers who were curious about how people make sense of a “simple” problem, i. e. having a cold. He asked people who suffered a cold to tell him what they thought and felt about their affliction. Five issues (dimensions, in illness perception research language) were consistently mentioned: what is it, what caused it, what can I do about it, what can a physician do about it, and how long will it last.⁶⁶ It seems that the dimensions assessed with the Brief Illness Perception Questionnaire (B-IPQ) are almost universally valid for all human beings. Kleinman listened to his respondents in smoky bars in Taiwan and the USA. In a study in New Zealand, Māori and New Zealand Europeans both held illness perceptions that fitted with the SRM,⁶⁷ although the two populations scored differently on a number of dimensions.

Second, the protagonist in the novel seems to respond to her diabetes with a mix of cognitions and emotions. Controlling the illness is high on her list. Desperation and anger appear the emotions that also play an important part in Peggy’s “doing diabetes”. The quotes that we selected clearly illustrate her struggle for control. These observations are remarkably in line with a recent ethnographic study of

⁶⁵ McManus: *Going to the Sun* (note 24), p. 121.

⁶⁶ Arthur Kleinman: *The illness narratives*. New York 1988.

⁶⁷ Deanna Sanders, Rob R. Kydd, Eva Morunga, Elizabeth Broadbent: Differences in patients’ perceptions of schizophrenia between Māori and New Zealand Europeans. In: *Australian and New Zealand Journal of Psychiatry* 45 (2011), pp. 483–488.

self-management by people with diabetes.⁶⁸ There the authors emphasise the great need of incorporating self-management into regular medical care.

Future research in the area of Medical Humanities (or LitMed) is a challenge as the theoretical and empirical basis of Medical Humanities is only at a quite young stage. Quite a few publications in the area seem to have a qualitative emphasis with sometimes even an active resistance against theory, methodology and quantitative data and data analysis.⁶⁹ Research with a strong theoretical and empirical emphasis, therefore, will help the area develop further, for example, the work on quantifying literary data.⁷⁰ Studying a novel might shed light on issues such as associations between illness perceptions and self-management behaviour, or on trajectories of illness perceptions. Topics such as “coping” or “social support” might also be subject of study in novels, poems, films, paintings or even music.⁷¹ Of course, as in our paper, the fascinating issue of how authors, poets, film directors, painters and composers are able to breathe life into the characters they create in their work remains a fascinating issue. Health psychology might very well benefit from close collaboration with fields such as literary theory or art studies.⁷² Teaching health psychology or Medical Humanities to medical or psychology students would benefit from using novels in order to study how people respond to and make sense of illness. Reading *Cancer Ward*, for instance, is much more informative about living with cancer than having to listen to psychology or oncology professors teaching about the topic.⁷³

We acknowledge limitations in our study. Selecting a novel and searching that novel for concepts from a theory, and then showing these concepts are present in the novel is like searching for white swans in a pond crowded with white swans.

⁶⁸ Susan Hinder, Trisha Greenhalgh: “This does my head in”. Ethnographic study of self-management by people with diabetes. In: *BMC Health Services Research* 12 (2012), p. 83.

⁶⁹ Rita Charon: Narrative medicine. Caring for the sick is a work of art. In: *Journal of the American Academy of Physician Assistants* 26 (2013), p. 8.

⁷⁰ Jenna L. Baddeley, Gwyneth R. Daniel, James W. Pennebaker: How Henry Hellyer’s use of language foretold his suicide. In: *Crisis. The Journal of Crisis Intervention and Suicide Prevention* 32 (2011), pp. 288–292.

⁷¹ Paul M. Camic: Playing in the mud: Health psychology, the Arts and creative approaches to health care. In: *Journal of Health Psychology* 13 (2008), pp. 287–298.

⁷² Thomas R. Cole, Nathan S. Carlin, Ronald A. Carson (Eds.): *Medical Humanities – an Introduction*. Cambridge 2014.

⁷³ Arundhati Ghosh, David A. Hirsh, Barbara Ogur, Steven David: Teaching medical students about cancer impact through a longitudinal surgical experience: A case study. In: *Teaching and Learning in Medicine* 24 (2012), pp. 158–162.

Nevertheless, the methodology that we applied is an additional approach to exploring perceptions of a medical condition. The number of novels in which diabetes mellitus plays a more or less prominent role is quite limited.⁷⁴ A highly interesting scientific enterprise would be to study a substantial corpus of novels on this subject and to paint, on the basis of this material, a picture of “living with diabetes”. That would allow putting a particular novel, such as *Going to the sun*, into a scientific and clinical perspective. In his learned monograph *Diabetes in Medizin- und Kulturgeschichte* von Engelhardt lists three additional novels on diabetes, and his work might be used for the purpose mentioned above. Von Engelhardt’s and our work may be instrumental in furthering the cause of literature and medicine concerning diabetes mellitus. This might also facilitate a “bottom-up” strategy in identifying themes that confirm the SRM but also themes that do not confirm the SRM.

A second limitation is the identification of quotes representing the various dimensions of illness perceptions. Defining and operationalizing the dimensions more formally (for example, with more than one rater) would improve reliability and validity of our findings, as would identifying other dimensions that may not be included in the SRM. This suggests an addition to the use of the SRM in assessing illness perceptions in novels (or poems, or patient interviews): how to operationalize and assess illness perceptions without questionnaires (whose psychometric qualities have already been established).

Given the state-of-the-art regarding self-management in patients with diabetes, it seems that incorporating illness perceptions in the medical encounter will be beneficial for patients and health care providers.⁷⁵ Hudson and colleagues demonstrated associations between illness cognitions and emotional health in a systematic review with meta-analysis of studies on how people with diabetes make sense of their illness.⁷⁶ McSharry, Moss-Morris and Kendrick in a systematic review with meta-analysis present “tentative evidence that illness perceptions in patients with diabetes can be positively changed through targeted interventions and that these

⁷⁴ The database LitMed lists four novels, in addition to memoirs, poems, autobiographies, essays, film, and video. www.medhum.med.nyu.edu/search?q=diabetes (accessed 3/14/2017).

⁷⁵ Harriet Bridges, Michael A. Smith: Mediation by illness perceptions of the association between the doctor-patient relationship and diabetes-related distress. In: *Journal of Health Psychology* 21, pp. 1956–1965; Hinder, Greenhalgh: This does my head (note 68), p. 83.

⁷⁶ Hudson, Bundy, Coventry, Dickens: Exploring the relationship (note 4).

changes may also impact on glycaemic control”.⁷⁷ Also, Thomas and colleagues show that “chronic care quality as defined in the Chronic Care Model, and consistency of chronic care with patient expectations (patient centeredness) was associated with illness representations favorable for good self-care management”.⁷⁸ Recently, we outlined how addressing illness perceptions in the context of the Chronic Care Model appears to be associated with positive effects on various behavioral and medical outcomes in patients with chronic somatic disorders, including diabetes.⁷⁹

The present study has important clinical implications: incorporating LitMed into the medical curriculum seems a worthwhile undertaking.⁸⁰ Empirical evidence for the positive effects of reading by patients (“bibliotherapy”) can be found, for instance, in a systematic review on reading by patients with neurological disorders,⁸¹ and in a study on reading by young girls with obesity.⁸² Increasingly, this knowledge is incorporated in the curricula of medical schools in the USA, Canada, UK, and the Netherlands.

A second clinical implication pertains to the issue of suicide. Suicide does play a rather significant role in the novel: two major characters decide to end their lives. This major issue raises moral and philosophical questions. Should suicide be seen as a coping response in persons with major illness? Should physicians or medical students discuss this issue in their hospital settings or medical schools curricula? Is it wise trying to prevent patients with diabetes reading the novel? These questions

⁷⁷ Jennifer McSharry, Rona Moss-Morris, Tony Kendrick: Illness perceptions and glycaemic control in diabetes: a systematic review with meta-analysis. In: *Diabetes Medicine* 28 (2011), pp. 1300–1310, here p. 1300.

⁷⁸ Thomas, Iyer, Collins: Associations (note 13), p. 50.

⁷⁹ Ad A. Kaptein, Jitske Tiemensma, Maarten J. Fischer, Margreet Scharloo, Antonia C. Lyons: Ongoing behavioural management of common chronic illnesses. In: Ed B. Fisher, Linda D. Cameron, Arthur J. Christensen, Uhle Ehlert, Yan Guo, Brian Oldenburg, Frank J. Snoek (Eds.): *Principles and concepts of behavioral medicine: A Global handbook*. New York (in press).

⁸⁰ Arno A. Kumagai: A conceptual framework for the use of illness narratives in medical education. In: *Academic Medicine* 83 (2008), pp. 653–658.

⁸¹ Julie M. Latchem, Janette Greenhalgh: The role of reading on the health and well-being of 43 people with neurological conditions. A systematic review. In: *Aging and Mental Health* 18 (2014), pp. 731–744.

⁸² Terrill Bravender, Alexandra Russell, Richard J. Chung, Sarah C. Armstrong: A “novel” intervention. A pilot study of children’s literature and healthy lifestyles. In: *Pediatrics* 125 (2010), pp. 513–517.

illustrate the value of using novels as material for different purposes, in various categories of people, in various positions in various societies.

Going to the sun provides an understandable patient narrative because it is fiction. Yet, our study shows that it does provide all the elements of a “real” patient narrative. Immersing oneself in patient narratives is a way for researchers and health care providers to boost their understanding of how patients make sense of and live with an illness. This in no way is a panacea for every health care provider, but some positive findings of encouraging health care providers to study the various art genres (novel, painting, film, music) in the context of illness have been reported.⁸³

Illness perceptions are formed quickly after diagnosis and are predictive of later psychological distress.⁸⁴ Fortenberry and colleagues demonstrate that illness perceptions tend to become more adaptive over time which is associated with better diabetes (self)management.⁸⁵ Therefore, assessing illness perceptions, evaluating their positive or negative content, and addressing unhelpful illness perceptions seems a worthwhile undertaking with a view to improving and stimulating self-management, with the intended consequence of improving the QOL of persons with diabetes mellitus. Applying these principles most likely will help current and future persons with diabetes. Peggy may not have gone to the sun for nothing.

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⁸³ Jakob Ousager, Helle Johannessen: Humanities in undergraduate medical education: A literature review. In: *Academic Medicine* 85 (2010), pp. 988–998.

⁸⁴ Timothy C. Skinner, Kamlesh Khunti, Marian E. Carey, Helen M. Dallosso, Simon Heller, Melanie Davies: Stability and predictive utility, over 3 years, of the illness beliefs of individuals recently diagnosed with Type 2 diabetes mellitus. In: *Diabetes Medicine* 31 (2014), pp. 1260–1263.

⁸⁵ Fortenberry, Berg, King, Stump, Butler, Pham, Wiebe: Longitudinal trajectories (note 14).