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Narrating the Lived Reality of Illness in Comics and Literature

Research by the *PathoGraphics* Team at
Freie Universität Berlin

The *PathoGraphics* project at Freie Universität Berlin is the first and, up to now, the only research group at a German university that focuses on illness narratives in both literature and comics. Funded since 2016 by the Einstein Foundation Berlin, *PathoGraphics* pursues research into the narrative and visual strategies, aesthetic choices, and ethical implications of representations of illness and disability in both media in order to foster a dialogue between literary and cultural studies, comics studies, critical health studies, the medical professions, and the wider society. By giving brief exemplary readings of excerpts from four English- and German-language comics, the article introduces the project's key questions, reports on both past and upcoming academic events and public activities, and outlines the project's publications.

The research project *Graphic Medicine and Literary Pathographies. The Aesthetics and Politics of Illness Narratives in Contemporary Comics and Literature* (acronym: *PathoGraphics*) analyzes the different ways in which the experiences of illness, medical treatment and disability are presented in fictional or (auto-)biographical literature and comics. From works of fiction to autobiographies and memoirs (often called “pathographies” [cf. Hawkins 1993; Frank 1995; Couser 1997]) to comics in the genre of “graphic medicine”¹ that speak from the perspective of a patient, a health care worker, or a family member, these narratives develop specific aesthetics to give shape to their understanding of the human condition. While the *PathoGraphics* research project takes a particular interest in comics and literary texts that focus on the lived reality of illness and disability from a multitude of angles, it does not limit its analyses to presumably ‘real’, (auto-)biographically based comics and literature but investigates supposedly less ‘authentic’ fictional works too. Our interest is always in the narrative and visual strategies, aesthetic choices, and ethical implications of the rich works of art in both media. With regard to illness comics, so far the vast majority has been published in the Anglo-American context, but relevant German-language works are gaining momentum.

Funded from 2016 to 2021 by the *Einstein Foundation Berlin* and affiliated with the *Friedrich Schlegel Graduate School of Literary Studies, Freie Universität Berlin*, the research project brings together expertise from various disciplinary backgrounds, such as German and English literature, gender studies, comics studies, science and technology studies, the history of medicine, disability studies, and

medical illustration. Academic lead Prof. Dr. Irmela Marei Krüger-Fürhoff (Institute for German and Dutch Languages and Literatures at FU Berlin) has published widely on the interrelations between literary and medical knowledge from the 18th century to the present. Einstein Visiting Fellow Prof. Susan Merrill Squier (PhD, Brill Professor Emerita of Women's, Gender and Sexuality Studies and English at Pennsylvania State University) is one of the leading international figures in the research field of comics and medicine and co-author of the seminal 2015 *Graphic Medicine Manifesto*; she spends time with the Berlin-based research team on a regular basis. Dr. Nina Schmidt, a literary scholar by training, recently published her dissertation *The Wounded Self: Writing Illness in Twenty-First-Century German Literature* on life writing and illness narratives (Schmidt 2018); and pre-doctoral researcher and graphic artist Stef Lenk pursues a practice-based dissertation on autobiographical comics and mental health.

The Ailing Body's Reality: Research Questions and Exemplary Analyses

During the first years of funding, the *PathoGraphics* team convened a series of academic events and organized a widely acclaimed comics exhibition; in addition, team members presented numerous scholarly papers and submitted several articles for publication in scientific journals and edited volumes. Examining English- and German-language works from cross-cultural and comparative perspectives, we asked – and continue to ask – questions such as: How do the spaces of the clinic, the private home, and the public realm interact in illness narratives? What different artistic strategies do literary texts and comics draw on, and what readers or viewers do they solicit? Are there situations in which one medium will be more effective than the other at communicating certain aspects of the illness experience, such as medical information, the emotional impact on an individual, or the social meaning of the experience of having a disability, receiving medical treatment, or giving care? How do comics convey the disruptive experiences of diagnosis, recovery, chronic ailment, or mortality? Do comics problematize medical diagnoses by drawing on media-specific strategies, such as creating dissonances between words and images (cf. Schüwer 2008; Hatfield 2009) or refusing to show details of (presumably 'abnormal') bodies to a compassionate or voyeuristic audience (cf. Williams 2015, 121)? To what extent does a comic's self-reflexivity entail a critical stance towards concepts of illness, health, and 'normal' embodiment (cf. Engelmann 2013, S. 109–194; Foss et al. 2016)?

Most written and visual-verbal illness narratives deal with one particular, clearly discernible medical condition (e.g. Alzheimer's disease, autism, bipolar disorder, cancer, eating disorders, epilepsy, HIV / AIDS, miscarriage, multiple sclerosis, obsessive compulsive disorder, Parkinson's disease, or post-traumatic stress disorder), enabling comparative readings across media. In addition, however, as a research group we seek to pursue systematic questions in order to

encompass historical, aesthetic, political, and epistemic aspects. The following paragraphs present some of the project's key inquiries across media and sketch exemplary readings of comics.

Confessing, Surviving, Normalizing: Constructing the Self in Illness Narratives

Many literary and graphic illness narratives rely on a confessional mode that can be traced back to religious treatises, autobiographies and literary fictions from Saint Augustine to the present, helping to establish a specific psyche and (bourgeois) subjectivity. The *PatboGraphics* project explores to what extent contemporary illness narratives reflect on these genre expectations, affirm, critique or subvert them. Do literature and comics conform to or go beyond the normalization process which is entailed in the confessional mode? How do recent literary texts and comics relate to cultural expectations of the “positive narrative arc” (Couser 2016, 4) of diagnosis, treatment, and healing (in the form of, at least, ‘spiritual’ progress)? How do they witness or imagine recurrent or chronic conditions that evade linear plot structures of survivorship and closure? What strategies do they use to convey the emotional aspects of invisible suffering, such as psychic disorders, trauma, autoimmune diseases or cancer?

A page from Ellen Forney's much-acclaimed graphic memoir *Marbles: Mania, Depression, Michelangelo and Me* on her life with bipolar disorder is a good case in point to show how a comic – as a medium that relies on both pictorial synchronicity and narrative continuity – can illustrate the experience of time that comes along with the lived reality of depression.² Using simple black lines, the wordless page (*Fig. 1* / Forney 2012, 77) shows the sequence of a lying figure enveloped in a blanket whose mere activity is to change rooms, move from bed to sofa, and from facing right to facing left before fusing with the furniture again. By combining visual repetition in a one-page tableau (signaling the experience of frozenness and stasis in synchronic time) with minimal variation (visualizing the diachronic flow of time through the sequence of 14 frameless images), the comic stresses the intractability of depression and the (at that very moment slim) chance of change.³ Similar to Virginia Woolf's 1926 essay *On Being Ill* (Woolf 2002) but in a much more condensed way, Forney's comic characterizes periods of (mental) illness as having a time of their own, while at the same time making the experience of slowing down in states of depression palpable to her audience.

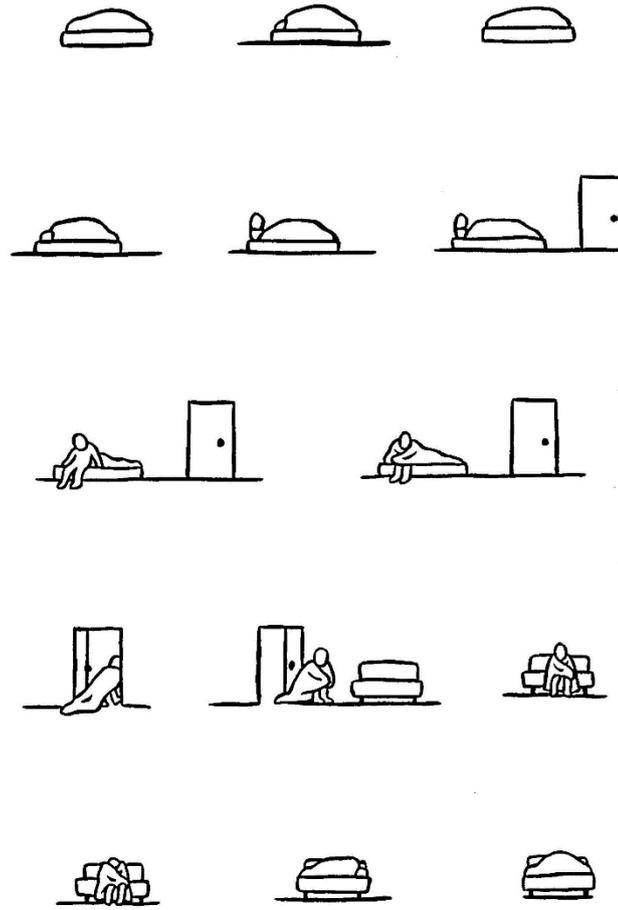


Fig. 1 (Forney 2012, 77)

Embodied Realities and Inner Landscapes: The Aesthetics of Representing the Lived Experience of Illness

Literary and graphic illness narratives offer insights into extraordinary bodily experiences, sometimes drawing on established philosophical and aesthetic traditions such as concepts of the sublime, the grotesque, the monstrous, and the abject (cf. Koch 2017; Schmidt 2018, 41-66). They incorporate intertextual and inter pictorial references to a wide range of cultural works in order to reflect on specific physical, mental, and social conditions and to counter the fundamental discomfort with illness and disability felt by ableist societies. How do authors and artists represent lived realities of illness which are shameful, taboo, or collectively suppressed? What strategies are used to narrate liminal experiences that may not be easily anchored in place or time, such as out-of-body experiences or failures of memory? Do autobiographical illness comics allow for a more ‘embodied’ approach to the narration of illness experiences because the drawn line which is used for the “pictorial embodiment” (El Refaie 2012, 8) of the main protagonist testifies to the suffering artist’s bodily interaction with the page (cf. Chute 2008, 457; Gardner 2011, 65)?

In this spirit, the cover of Peter Dunlap-Shohl's autobiographical comic *My Degeneration. A Journey Through Parkinson's* shows little attempts to gloss over the ailing body, displaying the cartoonist's loss of control upfront and with a sense of wry humor (Fig. 2 / Dunlap-Shohl 2015). His face is presented in shaky lines, with blurred features, and multiplied body parts, thus commenting on the contradicting experiences of bodily agitation and paralysis that are amongst the symptoms of Parkinson's. The cover might even be read as a reflection on the media-specific powers of comics as a hybrid genre: The textual level – that is the stable lettering of the title in a speech balloon – illustrates that a disease can receive a clear-cut diagnosis and become part of medical treatment; the pictorial level, however, complicates the bodily experiences represented and precludes a simple focus and prognosis (cf. Krüger-Fürhoff 2020).

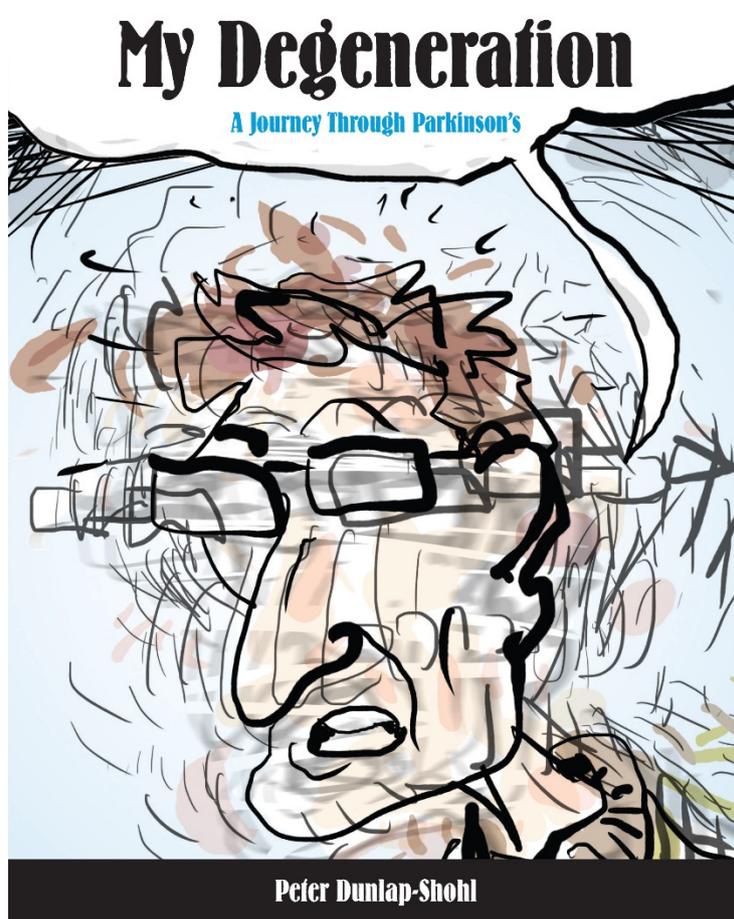


Fig. 2 (Dunlap-Shohl 2015)

The Politics of Storying Illness: Reassessing the 'Logic of Subversion' and Going beyond the Individual

We like to think of both literary illness narratives and graphic medicine as emancipatory and subversive *per se*. However, it might also be useful to look beyond the presumed 'logic of empowerment' and investigate how stories of illness and

health tie into recent efforts of bio-medical self-management, e.g. discourses on how to become a healthy subject within neoliberal societies that favor a logic of individual accountability, prophylaxis, and prevention. To what extent do the stories that literary and graphic texts tell – and the aesthetics they use – call into question, subvert or affirm Western societies’ expectations of compliant patients and individual disease-management? Can illness narratives give voice to the experience of entire communities or comment on national healthcare systems (and their potential flaws on a systemic level)? Are there texts and comics that offer alternatives to single protagonist narratives – if so, how do they do it?

In her comic *Patchwork. Frau Dr. Waldbeck näht sich eine Familie* [*Patchwork. Dr. Waldbeck sews herself a family*], Berlin-based cartoonist Katharina Greve draws on cut-and-paste strategies and intermedial references (for instance to Mary Shelley’s 1818 novel *Frankenstein* and its 1931 movie adaptation with Boris Karloff [cf. Shelley 1990; Whale 1931]) to tell a utopian story of xenotransplantation and animation: The comic’s main protagonist is an empathetic female version of Dr. Frankenstein who achieves her dreams of a family by stitching together discarded biological matter (*Fig. 3* / Greve 2011, 12-13). With much aplomb, the four newly-created do-it-yourself-chimeras and their ‘mother’ parody ideas of reproduction, concepts of socially acceptable bodies and sexual norms (only their names give the ‘children’ a specific gender) as well as notions of ethically acceptable medical procedures, social justice and responsibility in times of high-tech biomedicine (cf. Krüger-Fürhoff 2019).

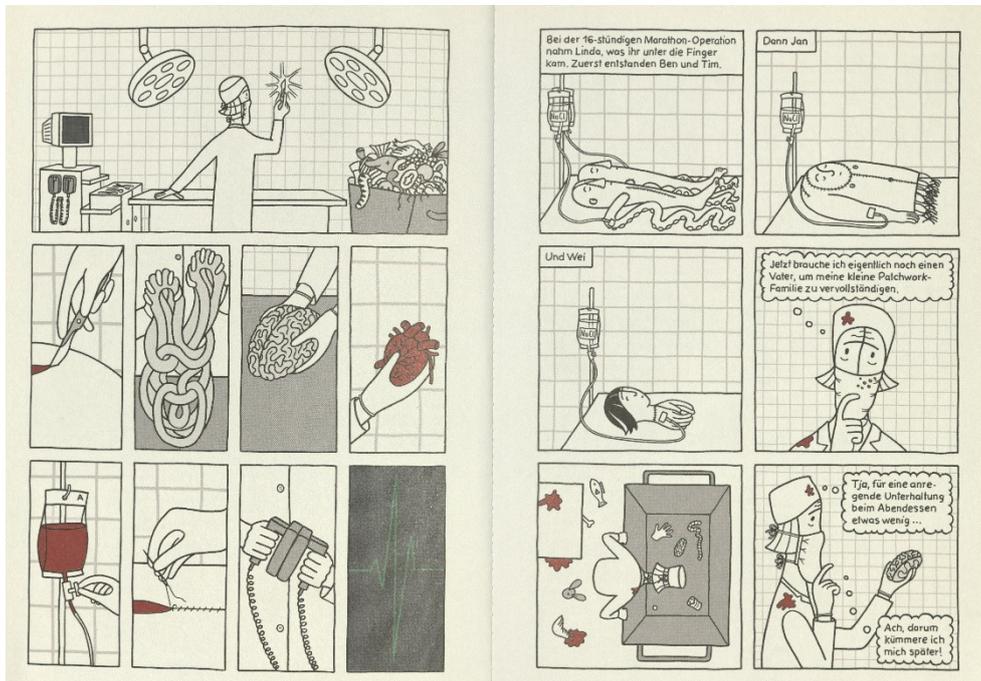


Fig. 3 (Greve 2011, 12-13)

Shared Spaces: Transdisciplinary Relations between Literature / Comics and Medicine and Care

With the establishment of narrative medicine and the critical health humanities, literature and comics are increasingly used to engage the public, impart new research or public health measures, and enable future doctors, nurses, and health care workers to better understand their patients, discuss internalized cultural assumptions and critically reflect on ethical issues in medicine. How do written and drawn illness narratives influence medical and scientific concepts of health and disease? How do these diverse spaces of experience and knowledge interact with each other? How do fictional comics and graphic somatographies participate in fostering a new ethics of care (cf. DeFalco 2016)?

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16 SEP 2008

This copy to:
Reproductive Medicine Clinic

CYTOGENETICS REPORT

Specimen	Surname	Date Of Birth	Sex	Reg.No.	Lab. No.
Blood	KNIGHT		F	X028874	C.08.06500
Date Taken	First Name	Consultant	Hospital	Pedigree No.	
22/08/2008	PAULA	Dr	Reproductive Medicine	Z.08.80838	
Date Received				Clin Genetics number	
25/08/2008				Not Known	
Clinical Summary			NHS Number		
RECURRENT MISCARRIAGES					

REPORT

Chromosome analysis revealed a normal female karyotype.

Karyotype analysis: 46,XX

REPORT

Chromosome analysis revealed a normal female karyotype.

Karyotype analysis: 46,XX

Comic Strip:

Panel 1: A woman in a white bikini celebrates with her arms raised. A speech bubble says "WooHoo!".

Panel 2: A dog is talking to a woman. The dog says "But am I a COMPLETE woman?".

Panel 3: A speech bubble says "I'm officially female!".

Signed: _____ Date: 10/09/2008

Unless otherwise stated, chromosome analysis is carried out using G-banding, supplemented with other techniques where appropriate.

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Fig. 4 (Knight 2018, 90-91)

In her 2012 one-page graphic work *I'm Female! (Cytogenetic test result)* (Fig. 4 / Knight 2018, 90-91), British artist Paula Knight uses two artistic strategies to appropriate her patient pathology report following recurrent miscarriages: She isolates and – with the help of hand-drawn red lines and arrows – recombines words and single letters from the clinical sheet. She further adds a two-panel comic that confronts the image of a jubilating woman with reflections on how – against all reassuring genetic test results – from a psychological and social point of view, successful womanhood is tied to being able to have a baby (cf. Squier 2017, 10-11). The text that thus emerges from the pathology report reads: “I heal / she is red / labor spit me out in to hospital / pedigree product not known number / blood is revealed / her state is supplemented with opiate”, linking her individual story to discourses of medical treatment, heredity, and pharmacology. Although the clinical results seem to reveal her true identity, the comics artist challenges the medical prerogative of interpretation – at the same time reframing her individual illness story within a larger cultural context.

Academic Events and Public Outreach: Introducing Illness Comics to a German Audience

In addition to academic activities in the context of the *Schlegel Graduate School* program, the *PathoGraphics* team convened annual workshops and international conferences. The aim of the inaugural workshop *Pathography and Graphic Medicine: The Genres of PathoGraphics* in October 2016 was to explore the ways in which artistic genres figure and operate in illness narratives and comics about medicine, illness and disability. The workshop participants asked: How are specific genres, such as life writing, confessionals and memoir distributed throughout literary narrative and comics? How do the different media of text and comics incorporate, enact, or revise generic traditions? What aesthetic expectations are coupled with these different genres, how do they play out in illness narratives and works of graphic medicine, and what are their social, historical, and biomedical implications? The *PathoGraphics* team invited eight comics artists and scholars (both early-career and established) from Germany, the United States, Great Britain, and Switzerland to discuss. Prof. em. G. Thomas Couser (Hofstra University) presented a public keynote lecture on “PathoGraphic Embodiment: Ethics, Politics, and the Visual Representation of Disability”.⁴

In 2017, the team curated the exhibition *SICK! Kranksein im Comic / Reclaiming illness through comics* at the Berlin Museum of Medical History at the Charité to introduce the growing genre of graphic illness narratives to a wider German audience and to initiate conversation among academics, artists, medical professionals, the comics community and the wider public. We had the great fortune of collaborating with art historian and curator Dr. Uta Kornmeier and Prof. Dr. Thomas Schnalke, director of the Berlin Museum of Medical History, who offered to display the comics amidst the museum’s collection of anatomical wet

and dry specimens founded by eminent pathologist Rudolf Virchow. This site enabled us to exhibit how art and science, individual stories and practice-based medicine, contemporary experience and historical knowledge can supplement and interact with each other. The short comics we displayed, many of them previously unpublished, were selected from submissions to an international call for art we issued. They focused on care relationships between children and their ailing (grand-)parents, burnout, chronic conditions such as Crohn's Disease, dementia, and depression, on infertility treatment, psychoanalytic therapy, and the intergenerational transmission of vulnerability and resilience. In a radical, critical and sometimes humorous way, the comics linked medical knowledge to the perspective of those who have become experts in the lived experience of illness, disability, and care. The exhibition panels combined each artwork with a short introductory text followed by a selection of terms relevant to understanding comics as a medium.

The exhibition *SICK! Kranksein im Comic / Reclaiming illness through comics* opened with keynote presentations by the founders of the graphic medicine movement (cf. www.graphicmedicine.org), the US-American nurse, blogger and comics artist MK Czerwiec and Ian Williams, a British physician and cartoonist. The exhibition (which was on display from October 2017 to March 2018) received widespread press coverage; announcements, reviews and interviews appeared in print and online newspapers (*Frankfurter Allgemeine Zeitung*, *Neues Deutschland*, *Der Tagesspiegel*), nationwide political magazines (*Der Spiegel*), on public radio and TV (*arte*, *Deutschlandradio Kultur*, *Radio Eins*, *rbb Kulturradio*), as well as in print and online journals from the areas of design, health and care management, public health, psychiatry, pharmacy, and dentistry. The bilingual exhibition catalogue is available as an open access publication (cf. Krüger-Fürhoff et al. 2017). In 2019, the exhibition will be shown again at the MuSeele, a museum of the history of psychiatry in Göppingen.

Alongside the exhibition, the international conference *Stories of Illness / Disability in Literature and Comics: Intersections of the Medical, the Personal, and the Cultural*, which we convened in October 2017, examined the ways in which knowledge and experience of illness and disability circulate within the realms of medicine, art, the personal and the cultural. Thirty-five speakers from nine different countries spoke on the topic from a variety of different perspectives, including literary studies, comics studies, media studies, disability studies, and health humanities. The keynote lecture was given by Prof. Leigh Gilmore (Wellesley College). A book publication including selected conference papers is forthcoming, to be published within Penn State University Press's Graphic Medicine Series (cf. Squier / Krüger-Fürhoff 2020).

In September 2018, the *PathoGraphics* team organized the workshop *Dementia, Violence, and the Politics of Memory in Contemporary Literature, Film, and Comics* in collaboration with Prof. Sue Vice from the University of Sheffield. The impetus for it was this: In public discourse and the day-to-day provision of health care, Alzheimer's disease and other forms of dementia are predominantly regarded as

illnesses afflicting individuals, and stories of dementia are not necessarily understood as entailing any wider political meaning. At the same time, however, memory loss can tie into political debates, especially in the context of World War II and the Holocaust but also in other experiences of racial / political violence and trauma in the contexts of colonialism, slavery, genocide, and forced migration in or across Europe, the Americas, and beyond. Memory theorists and cultural studies scholars have raised the fact that our memory culture will change once the eyewitnesses of 20th-century catastrophes have died. We asked: Should the increasing focus on protagonists with dementia in recent books and films be understood as related to this development? Is dementia in these contexts a simple plot device or is it used as a metaphor to raise larger cultural and socio-political issues? What are the political repercussions and the larger cultural impact of these works? Thirteen scholars from five countries delivered papers on literary texts, films, comics, and internet blogs; artist, writer, and medical anthropologist Dana Walrath (Vermont) gave a keynote lecture presentation on “Transmuting Transgenerational Trauma: Dementia, Storytelling, and Healing”. A collected volume based on this workshop and edited by Krüger-Fürhoff, Schmidt and Vice is in preparation.

Future Research Activities

From 2019 to 2021, the *PathoGraphics* team will seek to expand and intensify trans-disciplinary and trans-institutional activities in the context of healthcare training, the critical medical humanities, and patient empowerment, establishing closer bonds with the *Charité Institute for the History of Medicine and Ethics in Medicine*. In addition to the questions outlined above, we will pursue research on the social embeddedness of illness experiences, especially in written and drawn narratives of loss related to refugee trauma, bereavement, and dementia. We also plan to convene a workshop on perceptions of embodied time in illness and disability and a lecture series open to the wider Berlin public. For more information and upcoming events, see www.fsgs.fu-berlin.de/pathographics.

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¹ According to Ian Williams who coined the term in 2010, Graphic Medicine denotes “the role that comics can play in the study and delivery of healthcare” (cf. Williams n.d.). Subsequent publications add an increased interest in how comics show and tell experiences of illness, may alter cultural concepts of health, and engage in (political) discourses of care; cf. Czerwiec et al. 2015.

² For the powers of comics to capture the “enduring, if intractable, aspects of the patient experience” cf. Squier (2015, 46).

³ A more optimistic view can be found in Forney’s second comic which can be understood as a manual for being stable as a bipolar person; cf. Forney (2018).

⁴ Since then published as Couser (2018).