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The ›Affected Scholar‹

Reading Raina Telgemeier's *Ghosts* as a Disability Scholar and Cystic Fibrosis Patient

Dorothee Schneider (Kiel)

As an academic, I have often wondered how to bridge the divide between my emotions and personal experiences and the »dominant discourse of affectless rationality« that prevails in academic settings (Clegg, 71). The dominance of the supposed »scientific superiority of detached reason« and ›objective observation‹ over the ›emotional‹ and the ›subjective« (Greco & Stenner, 6) has never become clearer to me than when I confront works of fiction that feature characters whose stories resemble my own disability experience. Having been trained with that »particular view of rationality [that] remains discursively central to the idea of university« (Clegg, 71) in mind, I wonder how we as scholars with disabilities are supposed to deal with such works of fiction that affect us personally. Are we perhaps unable to write ›academically‹ about characters which go through experiences that might resemble our own disability experience too closely? Or should we openly confront the emotions these representations might trigger, in the same way that we clarify our theoretical assumptions? Is there a chance that we might even arrive at a deeper insight if we allow the personal to influence our research?

Feminist and postcolonial scholars have exposed the »objective« as the »unmarked positions of Man and White« (Haraway, 581) and, one should add, Heterosexual and Able-bodied. They have also discussed the relationship between emotion, or affect, and (feminist) theory (Pedwell & Whitehead), showing that scholarly interest in empathy and affect has risen in recent years (Donaldson & Prendergast, 131; see also Gibson or Coplan), with Monica Greco and Paul Stenner speaking of an »affective turn« (4). One discipline that has long placed the critical engagement with »affective experiences« at its center is disability studies (Goodley & Lilliard & Runswick-Cole, 206). Scholars like David Bolt have emphasized how bringing »experiential knowledge of disability« to analyses of »primary works« can facilitate a »deconstructive process [...] that often involves a subversion of ableist [...] binaries« (131). Following David Bolt's example, I will therefore use a (literary) disability studies approach for my analysis of Raina Telgemeier's graphic novel *Ghosts* (2016) – an approach

that enables me to integrate my personal experience of chronic illness and disability and my emotional involvement into my analysis. Thus, speaking from the position of an ›affected scholar‹, I will analyze the depiction of cystic fibrosis in the graphic novel. My choice of *Ghosts* is grounded in my interest in the way in which a – mostly – invisible illness like cystic fibrosis is represented in the visual medium of the comic.

Confronting Emotions in (Literary) Disability Studies

Disability scholars have argued over the role that emotions should be allowed to play in the discipline. Elizabeth J. Donaldson and Catherine Prendergast point out a central problem in this discussion with the subtitle »There's No Crying in Disability Studies!« to their 2016 introduction to a special issue on Disability and Emotion of the *Journal of Literary & Cultural Disability Studies*. Donaldson and Prendergast explain that while disability studies' efforts to move away from a depiction of disability entwined with tragedy and pity continue to carry a politically vital message (133), scholarship should »query what forms of emotion are allowed in our ›intellectual‹ work« (130). Their article underlines the importance of confronting our hidden emotional investments:

Renewed attention to the emotions is vital in Disability Studies for several reasons: to reveal the contours and limits of public discourse and the democracy it sustains; to recognize literary expression and persuasive tropes; to examine the hidden interests of architects of medical models; to represent the genesis and scope of Disability Studies itself (ibid. 134).

The aversion to (negative) emotions in the field is deeply connected to the roots of disability studies in the disability rights movement (Báar, 281f) that continues to fight against common ableist representations of disability as tragic or pitiable (Nielsen, 8). Ableism is a discourse that sets being able-bodied as the full state of being human and thereby casts people with disabilities as being less-than-human (Campbell, 5). Literary disability scholarship has actively sought to counteract these representations in the social realist tradition:

If the negative image results from associations of disability with personal failure, tragic loss, and excessive dependency, then social realists search for more accurate images that could effectively counterbalance this detrimental history (Mitchell & Snyder, 22).

The emphasis on the social model of disability that focuses on disabling social barriers and attitudes has moved the focus away from »details of impairment, such as the presence and persistence of pain« and »downplay[ed] the *effects* or *manifestations* of impairment« for people with disabilities (Kafer, 5), thereby also excluding their emotional responses to these effects. As Alison Kafer puts it aptly:

[M]y experiences as someone with a disabled body surely inform my work in disability studies. But how has my theorizing also been informed by the things I'm not supposed to talk about, by the feelings and reactions – by the mental and emotional distress – that do not yet fit within disability studies? (5)

And she adds: »A crip¹ refusal to see disability as tragedy, as traumatic, can just be as restricting on our politics and our theories as the ableist insistence that disability is always and only tragic« (Kafer, 6).

Like Kafer, who discloses her disability in her article and discusses its implications for her research, Donaldson and Prendergast also point out that they, like other disability studies scholars, often draw their inspiration from the personal realm, which bears the risk – or the opportunity – of bringing emotions tied to one's personal disability experience into one's research (129). Many scholars have been drawn to disability studies based on personal experience of disability or illness, which is certainly linked to the activist roots of the field. As Dan Goodley writes: »[O]ne should come to disability studies with a profound desire to understand and *change* the conditions of contemporary society. If not, why bother?« (34; my emphasis). Arguably, scholars are more likely to »bother« if they have personally experienced the limiting and denigrating effects of ableism. And, as mentioned above, bringing »experiential knowledge of disability« to the table can enrich our analyses and help dismantle ableist dichotomies (Bolt, 131).

However, one might still choose not to disclose one's disability², and indeed, academia might not be the ideal place for »coming out as disabled« (Samuels 2017a, 346) since »[t]he ideal of autonomous academic selfhood and the reality of the monadic workplace exclude the body« (MacArthur, 177). While Janet MacArthur feels that »not-quite not-other academics have a responsibility to speak out about these barriers in the workplace« (178) many fear rejection and keep silent in the face of possible repercussions. Revelations of one's disability, at least outside of disability studies, are often viewed as »narcissistic taboo excretions«, since disabilities are still mostly not visible in academia – in contrast to issues of gender and race that have been brought to attention in recent years (ibid. 178).

›Affected scholars‹ are, thus, confronted with a problem: bringing our personal background (read: our disability and/or chronic illness) into our research, especially when confronting the emotional side this background may include, may carry the risk of our research being unwillingly perceived as less valuable. The inclusion of emotions, such as passion or its absence into one's scholarship is generally viewed as carrying the risk of personalizing academic work and thus making it appear not only less than serious but »even as biased and unscientific —and thus as irrelevant, unimportant, or frivolous« (Neumann, 381). However, like Donaldson and Prendergast, Anna Neumann points to the concerns that this dismissal of emotions may cause, namely that such »deflection may weaken professors' scholarly endeavors and identities, especially if emotion and personal meaning help to constitute scholarly thought« (382).

As disabled scholars, with our identities and research interests intertwining, I believe we need to be able to express and explore our emotional involvement with our research topic. Similar to confronting our implicit theoretical assumptions, examining our emotional ties to a topic will lead to better, more reflective research. Opening up about having a disability and/or chronic illness in the field of academia can help make (further) visible the existence of disability in academia and add to a larger plurality of possible academic identities. Keeping in mind that traditionally, universities were »set up to exclude disabled people« (Mitchell & Snyder 2006, 198) and served as locations where »disabled people have been objects of study but not purveyors of the knowledge base of disability« (ibid), our openness will hopefully lead to more reflection on mechanisms of exclusion still at work in academic settings.

With these thoughts on identity, disability scholarship and emotions in mind, I will analyze the graphic novel *Ghosts* by Raina Telgemeier. *Ghosts*, a graphic novel written for children ages eight and upward (Kois, n. pag.), tells the story of two sisters, Maya and Catrina Allende-Delmar, whose mixed-race (latin/white) family moves to northern California because of Maya's health. Maya has cystic fibrosis and is thought to benefit from the saltier climate. However, the sisters soon discover that Bahía de la Luna, their new home, is a dwelling place of ghosts. Here, Catrina is confronted with the fear of losing her sister to her congenital disease; a fear that becomes entwined with the *día de los muertos* celebrations of the town and her own Mexican heritage.

Reviews of *Ghosts* were favorable, with the *New York Times* calling it a »heartfelt graphic novel, a typically empathetic and complex work« which »sensitively explores many dynamics of Mexican-American family life« (Kois, n. pag.). Critics have underlined the comic's engagement with loss and death (see Kois; Hansen; Frost; Spisak) and often highlight *Ghosts'* depiction of Mexican heritage and the *día de los muertos*, (see Ludtke; Kois), with one critic questioning the »harmful« appropriation of Mexican culture (Arredondo, n. pag.). The *Graphic Medicine*-review by Kevin Wolf briefly describes that cystic fibrosis plays a role in the narrative, and mentions that *Ghosts* uses magical realism to ask the question of »[w]hat might death mean to a child who understands their disease will shorten their life?« (n. pag.). However, more in-depth questions of the depiction of cystic fibrosis, such as the form of its portrayal, or even the question why cystic fibrosis was chosen for the narrative in the first place are not brought to attention by these critics.

Since other scholars, so far, have shied away from this topic, my analysis will focus more specifically on these issues and interrogate the role of cystic fibrosis in the narrative, as well as the specifics of its depiction in a comic. As both a cystic fibrosis patient and scholar in literary disability studies, my personal illness experience will affect my reading of *Ghosts*. I will show, however, that this will not limit or distort my reading of the graphic novel, but that my

»experiential knowledge« (Bolt, 131) of living with cystic fibrosis will instead provide another nuance to *Ghosts*' analysis.

Cystic Fibrosis³

To make my analysis of the depiction of cystic fibrosis in *Ghosts* easier to assess, I will briefly describe the underlying cause of the disease and its most common symptoms and therapeutic interventions. According to the Cystic Fibrosis Foundation, cystic fibrosis, often abbreviated as CF, is »a progressive, genetic disease that causes persistent lung infections and limits the ability to breathe over time« (CFF a). Cystic fibrosis is caused by a gene defect that causes the complete lack or malfunction of a transmembrane protein (the CFTR-protein) that normally transports chloride in and out of cells (Antoniou & Elston, 321). This leads to a build-up of thick mucus in the organs, mainly the lungs, but cystic fibrosis also affects the digestive system and the pancreas, often leading to malnutrition, liver disease and diabetes (Antoniou & Elston, 322). Therapies include airway clearance through nebulized saline, medication that helps liquefying the thick mucus, chest physiotherapy, and antibiotics to fight bacterial infections of the lungs (ibid.). With the progression of loss of lung function, patients may require supplemental oxygen, with a lung transplant as the final option for those in end-stage lung disease (ibid. 323). Patients with pancreatic insufficiency will usually eat a specific high caloric diet and require the intake of enzymes to facilitate the absorption of nutrients (ibid.). In case of severe malnutrition, tube feeding may help to maintain a good nutritional status (ibid.). Life expectancy for CF patients has risen continuously, with the median life expectancy for patients born in 2016 reaching 47 years (meaning that 50% of these children are expected to live to or beyond the age of 47) (CFF b). As Stuart J. Elborn writes: »The remarkable progress that has been achieved by improving airway mucus clearance and controlling lung infection has changed cystic fibrosis from being predominantly a disease of children to now being predominantly an adult disorder« (2521).

Even though cystic fibrosis is the most common autosomal recessive disorder in Caucasians (Antoniou & Elston, 321) with around 30,000 patients in the US alone and ca. 70,000 patients world-wide (CFF a), literary or filmic depictions of cystic fibrosis are rare. The few portrayals of CF in popular culture often seem unrealistic from a patient's perspective, for example by portraying characters in end-stage lung disease able to complete exhausting physical activities without showing signs of shortness of breath or coughing, or by giving inaccurate information about the disease (Dell, n. pag.).

In the next section of this article, I will analyze Raina Telgemeier's *Ghosts* in more detail. I will begin with a literary disability studies perspective on graphic novel, followed by an examination of the comic that factors in a reflection of my personal experience of living with cystic fibrosis.

»Cough cough, wheeze wheeze«:

Reading *Ghosts* from a Literary Disability Studies Perspective

Ghosts is one of very few (fictional) representations of cystic fibrosis in popular culture⁴ and among these the only longer graphic novel.⁵ Other than the fact that CF is generally not a very well-known disease, this lack of representations of CF might also be due to the difficulty of including a complex genetic disease into the plot without adding pages of medical background information. With regard to the comic medium, an additional difficulty that arises is that cystic fibrosis, on top of being a complex medical condition, can very well be described as an invisible illness. When not currently undergoing an exacerbation (meaning an active infection), cystic fibrosis patients can often appear healthy and pass as ›normal‹, even though some might be smaller and underweight for their age (The Lancet Respiratory Medicine, 823).

Raina Telgemeier solves the problems of invisibility and complexity through different strategies. When Maya is first pictured in the opening pages of the comic, her disease is not rendered visible and readers are only made aware of her CF by the comments of Catrina (called Cat), her older sister (e.g. Fig 1). While ascription of narration in comics is a debated issue, I will argue that in *Ghosts*, all of the verbal narration in captions can be attributed to Cat, who accordingly functions as a »narrator-as-narrating-character«, as described by Jan-Noël Thon (70). This becomes especially clear when regarding how Cat provides the necessary background information about cystic fibrosis that is set in captions at several points in the story : »Maya has cystic fibrosis. It's a thing you're born with. / It affects breathing and digestion. / And there's no cure« (5). Cat's medical comments on the opening pages are contrasted with the panel content, which shows a happy Maya eating »Frootzies« with gusto and singing along loudly to the radio (3;5).⁶ Right at the beginning of the narrative, an important distinction between two perspectives on cystic fibrosis is created. On the one hand stands the bleak medical perspective relayed through the narrator-character Cat (»[...] and there's no cure« (5)). On the other hand, we have Maya's positive spirit, represented through her singing that seems to drown out Cat's negative perspective, at least in the bottom panel of page 5, when the yellow speech bubble over Maya's singing obscures Cat's face and Cat's small caption is



Fig. 1: *Ghosts* (Telgemeier, 50).

the yellow speech bubble over Maya's singing obscures Cat's face and Cat's small caption is

confined to the bottom right corner of the panel. These two perspectives associated with the two respective characters are present throughout the entire narrative, with Cat's perspective mostly dominating over Maya's, as I will discuss in more detail below.

Another way of making cystic fibrosis visible in *Ghosts* is the inclusion of sequences of panels to illustrate Maya's treatments, and of drawings of her medical equipment in the back- or foreground of single panels. For example, the bottom panel on page 10 shows Maya's father setting up the living room in the new house and shows the air-pulse generator for her vest in the lower left corner of the panel.⁷ The equipment is then shown in use in a sequence that illustrates Maya's breathing treatment on page 14. A short action-to-action sequence in three small panels at the top of the page shows Maya setting up her vest with the help of her father (14) (cf. McCloud). This is followed by two broad panels in a moment-to-moment transition, with the long shape of the two bottom panels and the speech bubble that covers the entire upper length of the lower panel, illustrating the length of the treatment (cf. *ibid.*). The vibration of the vest is illustrated through multiple images of a singing Maya, the sound effects »shooka shooka shooka« and »VRRRRRRR« (representing the sound of the air-pulse generator) and the shaky lines of the letters in the speech bubble. A similar speech bubble is also visible in the next panel on the following page that contains an explanatory caption by Cat: »The vest helps loosen the mucus in her lungs« (15). In terms of representational agency, it is important to note that it is Cat, the healthy sister, who provides the anchorage, i.e. the »denoted description of the image[s]« that illustrate Maya's illness (DerikBadMan, n. pag.). While this helps readers understand what Maya is doing at points in the narrative, it also locates the interpretive power in Cat, not in Maya, the patient living with cystic fibrosis. Another example of such an action-to-action sequence that illustrates the treatment regime of cystic fibrosis is the preparation of the nutrients that Maya takes overnight via gastrostomy tube (called a g-tube) (50; cf. Fig. 1).



Fig. 2: *Ghosts* (Telgemeier, 15).

This sequence again focuses on Maya's positive personality and compliance and shows Maya happily shaking up the nutrient mixture (50). Even though Cat introduces the sequence in another caption (›Because cystic fibrosis affects digestion, Maya doesn't always get enough nutrients from food / so she has to get them another way‹) she provides no other medical details or anchoring, such as naming the g-tube, even though we see a close-up of the ›button‹ g-tube to which Maya connects the feeding pump. So even though this sequence introduces another component of CF therapy, it functions mainly as an instance of characterization of Maya.

This strategy of placing characterization over medical accuracy also becomes clear with regard to Maya's breathing treatments. As illustrated above, using a nebulizer is one of the essential treatments for airway clearance in CF patients and often goes along with the vest treatment but Maya does not seem to use one. The use of a nebulizer, which creates small cloudy puffs of mist, could very well have been used to visualize the treatment of the disease and the importance of breathing that Telgemeier illustrates through sound effects like ›Hff-ffff‹ and ›Hwooooooh‹ (for breathing in and out, 25 and 26 resp.). Instead, Maya is vocalizing a loud ›LA-A-A-A-A‹, which resembles her singing and, again, highlights her positive spirit that she retains throughout her treatments, which is further underlined by the size and red color of the letters (Fig. 2).

Other than direct representations of Maya's treatment, Telgemeier also uses visual metaphors to illustrate the impact of cystic fibrosis on Maya and her family. As Maya's illness progresses, she needs more medical equipment. After she returns home from a hospital stay, she requires supplementary oxygen. When Cat enters her room, the coils of Maya's nasal cannula lie on the floor before her feet, illustrating how Maya's disease threatens to ›entangle‹ Cat, who tries to keep her fears about Maya's illness at bay (114, Fig. 3). Maya's disease, even though it is not constantly emphasized, is a continual undercurrent in the family's

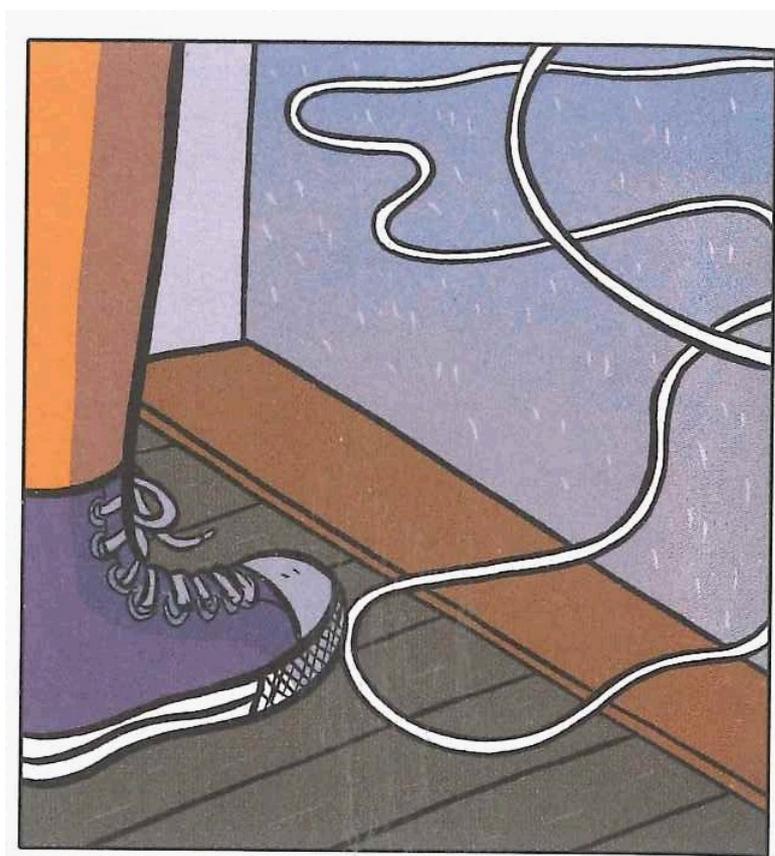


Fig. 3: *Ghosts* (Telgemeier, 114).

daily life. This is also exemplified by Maya's medical equipment that is often part of the panel background and not always shown in use (e.g. 60).

In the previous panels, when Maya is not yet oxygen-dependent and her disease is not visible in public (her treatments take place in the privacy of the family's living room or in her bedroom), sound effects are used to illustrate her CF. Maya's difficulty breathing after running down some stairs to the beach is illustrated with »wheeze wheeze« and a coughing fit is shown with the words »cough« and »hack« in different fonts and sizes (13, Fig. 4). When Maya is out of breath, she doubles over and »pant, pant« is written next to her (145), thus visualizing her breathlessness.

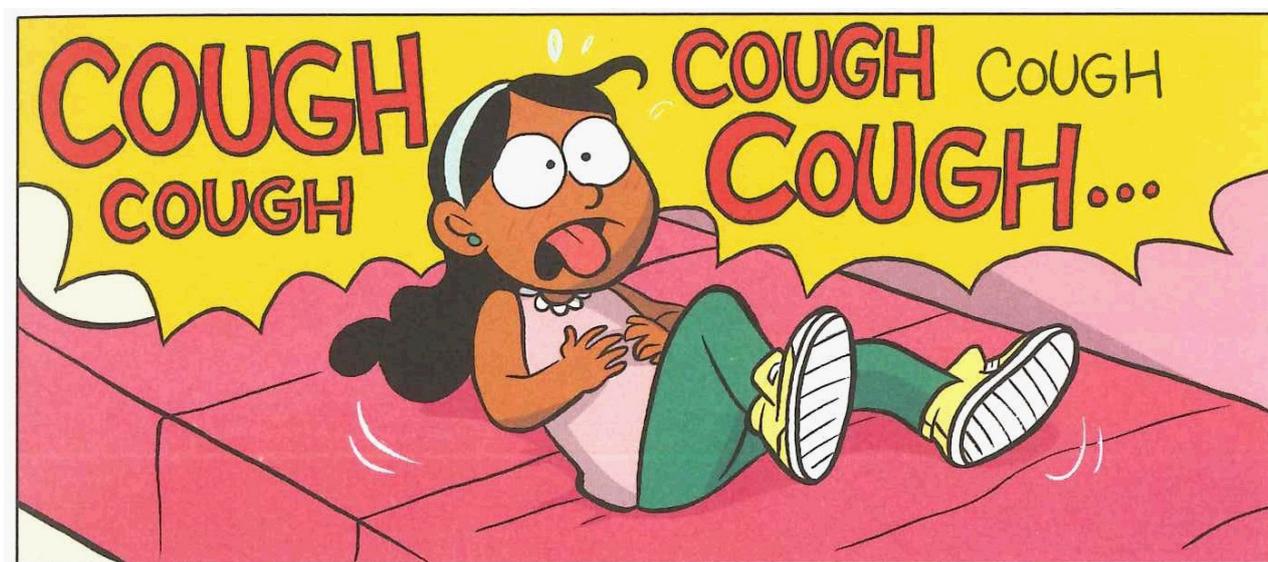


Fig. 4: *Ghosts* (Telgemeier, 13).

Even though Maya's health deteriorates in the course of the narrative, the representation of Maya's character and her general physique do not change in the course of the graphic novel. The comic focuses on Maya's consistency as a character rather than on the physical changes caused by the progression of disease, such as possible weight-loss, paleness, or even a red face caused by a coughing fit. The color palette of the comic, however, does change occasionally (cf. Spisak, 603). A change to darker hues is especially prominent when a very sick Maya comes home from the hospital and Cat worries whether or not she will get better again (114) – and changes to lighter colors once Maya has recuperated (137). Here, »character-bound focalization« (Horstkotte & Pedri 335) can clearly be ascribed to Cat, because the »storyworld« »[is refracted] through the protagonist's mental life« (ibid. 339).

Through comic specific techniques, such as capturing Cat's explanations in captions, the panel sequences showing Maya's treatment and depicting the treatment equipment in the background of panels, the graphic illustration of metaphors and sound effects and changes

in color, the comic visualizes the different invisible symptoms, treatments and the impact of cystic fibrosis on Cat and her family in a way that is accessible for readers who are not familiar with the illness. However, the representation of health and illness in the comic is largely dependent on Cat. Her »mind style«, that is, the systematic choices of representation and the language in which these representations are framed in the comic (Mikkonen, n. pag.), for example through the captions and the color palette, forms the primary lens through which Maya's cystic fibrosis is represented. This shows a discrepancy in narrative agency that gives representational power to the healthy sister and makes Maya mostly an object, rather than a subject, in the narrative. Having examined the representation of health and illness, I will now turn to a closer examination of the plot and narrative of *Ghosts*.

The story of *Ghosts* is set in motion with a change caused by Maya's illness which affects the whole family: The Allende-Delmars move from Southern to Northern California to »this gloomy place« (6) Bahía de la Luna, where the colder, salty climate is thought to be beneficial to Maya's health. Cat's first reaction to the relocation is to exclaim »Ew, I'd rather die!« (6). As the shocked reaction of her parents and sister shows, death and the emotions connected to it are a taboo topic for the family. Apparently, the move to Northern California is not only thought to improve Maya's health but also to prevent her early death, which the family seems to assume to be very likely. This fear is underlined by Cat's clarification: » „Of course I don't want to die. And I want Maya to be as healthy as possible. Duh!« (7). The narrative thus connects the move to Maya's disease and her reduced life expectancy. As the story progresses, it turns more directly towards Cat's fear of Maya's death, which is illustrated through the comic's »magical realis[ist]« (Wolf, n. pag.) engagement with the Mexican *día de los muertos* tradition.

Maya and Cat's family, even though their maternal side has Mexican roots, has not celebrated the day of the dead until this point, which is explained by the mother's difficult relationship with her grandmother that lead to her rejection of Mexican traditions (57f). However, this refusal also seems consistent with the family's general lack of engagement with the topic of death. Maya and Cat learn about the *día de los muertos* celebration in their new town from their Latin neighbors, who explain that they throw the ghosts »a big party, with the best music, dancing, and food« (47). This positive attitude towards death contrasts sharply with the silence that surrounds the topic in the Allende-Delmar family. Since Maya's parents do not seem to be able or willing to discuss the topic of death with her, and the option of a lung transplant is not explored, both Maya and Cat are confronted with Maya's impending death, without the possibility of voicing their emotions connected to this.

However, Maya and Cat soon find out that Bahía de la Luna is frequented by actual ghosts that are drawn as »floaty, sea green, protoplasmic beings« (Hansen, n. pag.). The graphic novel's magical realism allows for the insertion of the ghosts into the intradiegetic reality of the novel and thus gives Maya and Cat the possibility to confront the topic of death through their engagement with the ghosts as the manifestations of deceased people. While the medi-

of the story this misrepresentation has a function: Maya's sudden decline is caused by her contact with the ghosts that signify her closeness to death and her hospitalization underlines Cat's fear of losing her sister as well as her attempts to protect Maya and herself from confrontation with the topic of death. As becomes clear here, the focus of the narrative lies not so much with cystic fibrosis but rather with the anxiety of loss that is central to Cat. As Carlos explains later: »If you share a tiny bit of your own breath ... sometimes they'll speak to you«, to which Cat only retorts, angrily: »Speak to you about what? Coming to join them?!?« (106).

The first meeting with the ghosts illustrates the different perspectives that Cat and Maya have on death and cystic fibrosis. Even though the ghosts are drawn as happy, almost human-looking skeletons with individual faces when they interact with Maya (Fig. 6, 94), from Cat's perspective they appear as shapeless, faceless blobs. As April Spisak points out in her review, the characters need to »make a connection with an individual« after which the ghosts take on the skeleton form (603). The subject-to-subject sequence of their first encounter with the ghosts again illustrates the differences in perception between Maya and Cat. Cat's fear keeps her from seeing the ghosts' individual forms; to her they are indistinguishable and appear to be threatening Maya (99), while Maya can interact with the happy ghosts. Maya, in contrast to Cat, seems to regard death and her own shortened life-expectancy with positivity and curiosity and the smiling skeletons she can see mirror this attitude. The ghosts, literal manifestations of death, and still in their form of shapeless blobs, keep following the fearful Cat around and also appear at the family's house. Cat tries to outrun the ghosts and when she later shouts at the ghosts »MAYA'S / NOT / READY!!!« (124), it becomes clear that she cannot face her sister's possible death and is haunted by it (Fig. 7, 124).

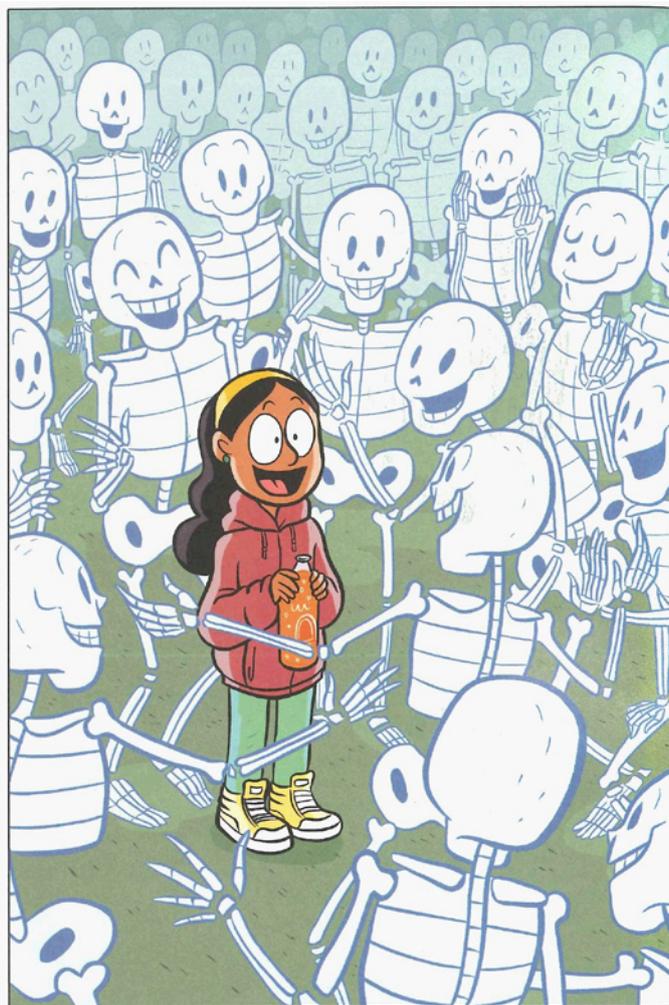


Fig. 6: *Ghosts* (Telgemeier, 94).

This point also illustrates one of the central issues of the comic, namely its narrative situation that I have commented on before: *Ghosts* is almost solely told from the perspective of Cat. While Cat herself is healthy,⁸ she knows quite a lot about cystic fibrosis and its treatment and provides necessary background information for the implied reader of the comic, who is not familiar with cystic fibrosis. And while the graphic novel thus gains a didactic function and gives a small insight into the daily life of a cystic fibrosis patient and the struggles that this brings to families, and especially healthy siblings, through Cat's perspective, the story only uses Maya as a focalizer in a few instances. Thus, the narrative misses the opportunity to gain more insight into an otherwise rather flat character, who is very much defined by her disease. And, as discussed above, it ascribes the interpretive agency of what it is like to live with

cystic fibrosis to the healthy sister and not to the patient. Thus, the comic mostly silences Maya. As Goodley, Liddiard and Runswick-Cole point out, this voicelessness is a common problem: »young people with ›life-limiting‹ or ›life-threatening‹ impairments (LL/LTIs)« (197)

are living longer than ever before, yet we know little of their lives, particularly from their own perspectives. This lack of knowledge is due to the marked absences of this unique group of disabled young people from public imagination and broader culture. Young people with LL/LTIs have been omitted from much academic research; are seldom explicitly written into public policy; are often excluded from disability communities and disabled people's own movements; and have their voices dominated by professional perspectives within palliative (end-of-life) care teaching, education and training (205).

In *Ghosts*, it is Cat's medically influenced fearful perspective that dominates Maya's perspective on her illness. At the beginning of the narrative, we as readers do not get to know whether or not Maya's disease frightens her or makes her sad, although we do learn that she is curious to know what happens after death. Maya is generally portrayed as a very happy, playful child who is extremely compliant in terms of her therapy, and never resists the treat-



Fig. 7: *Ghosts* (Telgemeier, 124).

ment. In fact, the only negative emotion that the narrative allows Maya to express with regard to her cystic fibrosis is sadness. Anger and fear are almost exclusively reserved for her sister. The only central point in the comic when Maya explicitly expresses negative emotions about her CF is when she is not allowed to go trick-or-treating for Halloween with Cat, after her health has deteriorated: »What was the point in moving here, Mom? / We came to Bahía de la Luna so I could be healthier, right? So I could actually do stuff – [...]// It's not like I'm ever going to get better. [...] / So why not let me have fun while I can?« (162f). During this exchange, Maya wears her Halloween costume, an angel costume with wings and a halo



Fig. 8: *Ghosts* (Telgemeier, 162).

(Fig. 8) symbolizing both her vulnerability, innocence and her closeness to death. The window behind which Maya is pictured adds an additional frame to the panel that makes Maya appear imprisoned, underlining the hopelessness of her situation and her exclusion from the ›normal‹ outside world. In the cystic fibrosis community, the death of a member is often circumscribed in the words: »S/he gained her wings« which makes Maya's costume an explicit link not only to death but to death by cystic fibrosis. It also underlines her angelic nature and compliance that is stressed throughout the narrative. Maya's mother describes Maya's attitude as follows: »Every time she has a setback, she seems to rebound with twice the positive attitude« (115). And according to Cat »[Maya's] soul doesn't need any loosening [...]« (15; cf. Fig. 2), characterizing her as an optimistic and cheerful person. The fact that this statement is directly connected to her treatments for her CF (loosening the mucus in her lungs, 15) underlines the implicit assumption that because of her disease, one might expect Maya to be sad or unhappy. However, her positive personality is intricately connected to her cystic fibrosis and Maya is not happy and optimistic in spite of but *because* of her illness.

Overall, *Ghosts* portrays Maya as ›wise beyond her years‹. The angel costume, which she wears during the last third of the graphic novel, explicitly underlines her role of a prophet or bearer of wisdom. This becomes clear when she asks Cat to return to *día de los muertos* celebration to talk to the ghosts to overcome her (i.e. Cat's) fear of death: »But don't do it for me... / Do it for yourself« (176). Throughout the narrative, she continually calms down her

sister by telling her to breathe (25f; 177). Her favorite »Princess song« (26) seems to be a variation of the FROZEN theme song »Let it go« (with the text »Let it out, let it out, can't hold it in gotta shout«)⁹. Apparently, Maya has altered the words of the song to fit her own experience, which further underlines her wisdom. As mentioned above, it appears that her disease has made her curious of death but in contrast to her older sister, she seems to have accepted her fate of having to die young. This is already shown at the beginning of *Ghosts* when Maya tells her sister that »Dying isn't pretend, Cat. It's real« (72). Rather than worrying about the process of death or how much time she might have left, Maya worries about her sister and the impact her death will have on Cat. We learn this when Maya meets the ghost José later in the comic: She then selflessly voices her concerns about her sister not being able to make any new friends once she (Maya) has died (224f.), instead of asking her primary question of what happens when you die (72). This illustrates how the focus of the narrative clearly lies with the older, healthy sister Cat and her emotions regarding Maya's death.

Even though Maya also asks about herself being able to make new friends after her death, any other concern for her own well-being, fears about having to suffer pain, or anger and grief about having a reduced life expectancy are not addressed by Maya. Instead, José talks to *Cat* about how he died and what dying is like (201f.). The reader and *Cat* receive the comforting information that dying for José was simple and painless (»One minute I was me ... / the next minute I was still me but like this [a ghost]« 202). This information would certainly have given comfort not only to *Cat* but to Maya as well. However, Maya happily accepts José's assertions that there are »certain benefits to being a ghost« (ibid.), namely the freedom from physical constraints: »We [ghosts] can run faster / jump higher / and dance longer than any mortal [...] although we do get a little winded sometimes ...« (226, Fig. 9). Maya can,

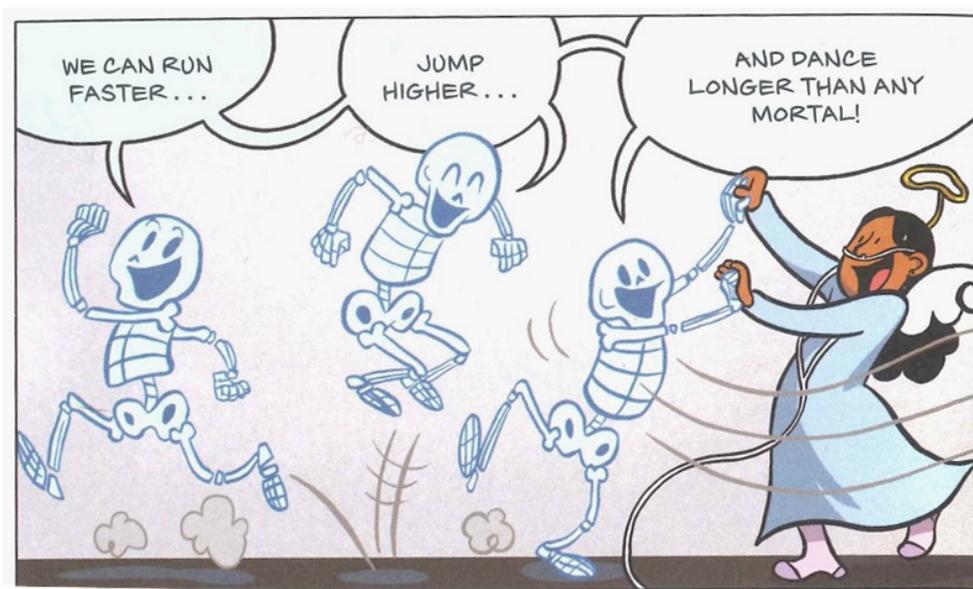


Fig. 9: Ghosts (Telgemeier, 226).

of course, empathize with being out of breath and offers José her oxygen tube. The oxygen energizes José, who excitedly bounces through the room and the meeting ends on a happy note. José, who died at age eight (200) and is roughly Maya's age, and who likes to bounce around making cannonballs (214), just like Maya (13) is yet another link that connects Maya to death. At the same time, José provides the example of a happy ghost and, thus, a positive image of death for the two sisters. Together with the idea that Maya will be free from shortness of breath and be even physically fitter than any mortal after her death creates a positive outlook for Maya and the encounter comes as a relief for both sisters. For Cat, the magical confrontation with her Mexican heritage in the form of the ghosts helps her find a more positive connection to death. Still wearing the »La Calavera Catrina« costume¹⁰ (BBC, n. pag.) that connects her to the positive attitude towards death in Mexican culture that Telgemeier constructs in *Ghosts*, she starts making hopeful plans for the future: »Next year you've got to come to the party with me« (233).

As I have illustrated above, the narrative's focus does not lie with the representation of cystic fibrosis, but with a more general overcoming of the fear of loss and death. This is underlined through the narrative agency of the healthy Cat and the overall amount of representational energy that is invested in the symbolic rendering of death through the *día de los muertos* and the ghosts and that takes far more room in the narrative than the few panel sequences that illustrate cystic fibrosis. Therefore, *Ghosts* might ultimately be read as suggesting that dying and becoming a ghost (at least in the story world of the graphic novel) might be preferable to the reality of living with cystic fibrosis. In the next section, I will examine the function of cystic fibrosis in *Ghosts* more closely.

»Cough cough, wheeze wheeze« (again): Reading *Ghosts* from a Cystic Fibrosis Perspective

Having analyzed *Ghosts* from a literary disability studies perspective, I will now regard the comic from my position as an ›affected scholar‹. Since I am a cystic fibrosis patient myself, I bring my identity and personal illness experience as well as my emotional entanglement with cystic fibrosis to my analysis of *Ghosts*, which gives me the possibility to bring a different angle to my reading.

While reading *Ghosts*, I wondered why Raina Telgemeier chose cystic fibrosis as a disease for Maya in the first place. Since cystic fibrosis patients may benefit from saltier sea-side climate (Peck, n. pag.), Maya's disease gives an incentive for the Allende-Delmar family to relocate to Northern California, which sets the graphic novel's story in motion. Other than that, cystic fibrosis is an autosomal recessive disease which lets Telgemeier construct a family with two healthy parents and one sick and one healthy child, so that her narrative can explore the

impact that the disease has on the healthy older sister. Additionally, cystic fibrosis is a fatal disease, which enables Telgemeier to narrate a story around a character that very early in her life is confronted with the possibility of dying.

In the afterword Telgemeier herself writes: »I chose to write about cystic fibrosis because breathing is a huge theme in this story. Ghosts can't breathe and Maya can't breathe very well herself. Cat has normal lungs, but she is often anxious and sometimes needs to be reminded to stop and breathe deeply« (243). This explanation illustrates that Maya's disease has a metaphorical function in the story. Choosing cystic fibrosis as a disease that causes breathlessness lets Telgemeier connect Maya to death through the figures of the ghosts that personify death and that Telgemeier also characterizes as out of breath. Thus, cystic fibrosis ultimately comes to signify death by analogy. In contrast to Cat, who is literally breathless with fear for her sister, Maya is represented as fearless – in spite of her breathlessness from cystic fibrosis. This also becomes clear in the scenes when Maya has to remind Cat to breathe in an attempt to calm her down (25; 177) and shows a reversal of roles, with the younger sister taking care of the older. Thereby Telgemeier shows that Maya tries to pass on her calmness to her older sister, which suggests that she – in contrast to Cat – has accepted her cystic fibrosis and, thus, her shortened life expectancy.

Being confronted with our own mortality is not easy. I was around six years old when I understood that cystic fibrosis is a fatal disease. I have been lucky enough to defy doctors' predictions that I would not live past age 18, but constant insecurity with regard to my future takes its toll. Maybe not surprisingly, given this constant insecurity, a third of adults with CF suffer from anxiety and »studies have documented rates of depression ranging from 8% to 29% in children and adolescents and from 13% to 33% in adults [with CF]« (The Lancet Respiratory Medicine, 823). Having cystic fibrosis comes with a complex bag of emotions, not all of which are represented in Raina Telgemeier's comic. While I can empathize with many of Maya's experiences, such as her frustration over not being able to participate in an activity because of her health, the emotions with which Maya regards her illness seem reductive. Maya never complains of fatigue or pain (such as stomach aches from fatty food combined with wrongly dosed enzymes), or is annoyed about the long periods of time spent doing treatments or attending care center appointments. She rarely seems to be sad about her disease and does not express fear of the future. While Maya is allowed to express sadness, she does not seem to feel emotions like fear, anger or grief that might stand in contrast with her positive nature. *Ghosts'* narrative thus reduces the complexity of possible emotions felt by cystic fibrosis patients to occasional sadness and optimism, mostly disregarding emotions such as anger or fear that might characterize difficulties of accepting life with CF. This reduction, along with her angelic compliance with her medical regime and her happiness turn Maya into an object of inspiration for non-disabled readers.

While Maya's physical treatments are mostly accurately portrayed, the narrative also shies away from other bodily aspects of cystic fibrosis, such as problems of indigestion or the fact that the vest is used to cough up (and spit out) the sticky mucus that clogs the lungs. Although this may not be appealing information for the reader, given its didactic angle, the graphic novel could also have helped to normalize these aspects of CF life, which are often associated with shame or discomfort.

Maya's character seems to be modeled on Telgemeier's cousin Sabina Costello, who died of cancer, aged thirteen and who Telgemeier characterizes in her »Thank you« as »one of the most inspiring kids I ever met: spirited, joyful, and not interested in letting her illness define her or slow her down« (246). While I do not intend to question Telgemeier's portrayal of her cousin, the reduction of sick or disabled characters to inspirational characters is a stereotypical disability trope and has rightly been challenged as »inspiration porn« by the late Stella Young:

And I use the term porn deliberately, because they objectify one group of people for the benefit of another group of people. So in this case, we're objectifying disabled people for the benefit of nondisabled people. The purpose of these images is to inspire you, to motivate you, so that we can look at them and think, ›Well, however bad my life is, it could be worse. I could be that person‹. (Young, TEDxSydney).

Inspiration porn thus reduces disabled people to a mere inspirational narrative function and these fictional representations in turn influence the real-life perception of actual people living with illnesses or disabilities. As Brad Dell, another cystic fibrosis patient, aptly points out, the struggle of having to appear heroic or inspirational and not being able to express negative emotions can actually be damaging because it may force us to hide our suffering to fulfill the hero role (Dell b, n. pag.), and it may make us more reluctant to seek help for mental health concerns.

While the term ›inspiration porn‹ might not do full justice the more nuanced portrayal of Maya in the course of the novel, she is, contrary to Telgemeier's cousin, very much defined by her disease. In terms of the emotional side of cystic fibrosis, the focus of *Ghosts* lies clearly with Cat's acceptance of her sister's disease and the overcoming of her fear of death, and not with the emotional struggles that Maya might face. As I have outlined above, the narrative focuses instead on Cat's journey towards accepting her sister's illness and early death, which she achieves through her involvement with her Mexican heritage during the *día de los muertos* celebrations, which, in the end, makes *Ghosts* a narrative that uses cystic fibrosis as a plot device, but that is not, specifically, about life with CF.

Ghosts, even though it focuses mostly on the healthy Catrina, is also an illness narrative, or ›sick-lit‹. Many people experience illness as »an interruption of their lives« based on the assumption that »illness is temporary, of short duration, and with a predictable outcome: recovery« (Charmaz, 13). This trope also structures the illness narrative (Schubert, 266).

However, when illness becomes chronic, these assumptions and the narrative of »illness as interruption« no longer work. People with chronic illnesses or disabilities often live outside of a »linear progressive time with its normal life stages« (Samuels 2017b, n. pag.). We experience impairments in the present for which we are deemed too young, and, specifically with cystic fibrosis, »[we live our] entire lives near, at, or even a few years beyond [our] assumed life expectancy« (Schubert, 266), which results in »an absence of a long-term future« (ibid., 269).

This lack of a future might be another the reasons why cystic fibrosis lends itself to the narrative of *Ghosts*, because the shortened life expectancy might make one assume that CF patients live more in the moment and enjoy life more consciously, as the characterization of Maya suggests. I cannot speak for other cystic fibrosis patients, but I agree with Michele Lent Hirsch that popular culture often portrays people who have been confronted with their own mortality as »more alive and seize-the-day-y« than others (201) – a characterization of us that I see as detrimental for patients with chronic illnesses. Trying to enjoy life to the fullest is certainly a great concept – as Maya puts it: »Why not let me have fun while I still can?« – but the requirements of the small everyday things and the demands of our bodies to take breaks (cf. Samuels 2017b, n. pag.) make it hard to always make the most of every day. Cystic fibrosis is a demanding disease in terms of time spent doing treatments and one of its effects can be chronic fatigue (Jarad et al., 241) that makes it hard to always live life to the fullest, especially if the outside expectation is that we should be »inspirational« and never let our disease »define us«, as Telgemeier writes about her cousin (246).

But even though cystic fibrosis is a difficult disease that shortens life, patients usually do no longer die in early childhood. In her afterword, Telgemeier writes: »While there is no cure, improved treatments for CF have greatly extended the life expectancy of patients« (243). However, in *Ghosts*, CF is portrayed as a disease that leads to death in childhood, and that has no treatment options once a patient's lungs have deteriorated beyond a certain point. The possibility of a lung transplant, an option which »should be considered for all patients in end-stage lung disease« (Antoniou & Elston, 323), is not explored further in the narrative, but could have provided a more hopeful lookout for Maya. *Ghosts* (2016) also does not mention medications, available since 2012, that specifically target the underlying genetic causes of cystic fibrosis by modifying the faulty CFTR-protein have been introduced, which have shown a significant improvement of lung function and reduction of infections in CF patients (Fajac & De Boek, 206), another point that could have given the story a more realistic, hopeful perspective. Since there are so few existing fictional portrayals of cystic fibrosis, it should be even more important to give a more well-rounded depiction of the disease that does not reduce cystic fibrosis to a narrative prosthesis.¹¹

Conclusion

Analyzing *Ghosts* both from a literary disability studies perspective and with my personal illness experience in mind, I have shown that bringing one's personal experience and emotional involvement can actually create a productive, critical reading of a fictional text and that confronting our disability identities and emotional involvement needs not make our readings unscientific or reductive. Since *Ghosts* does not give the patient Maya much of a voice, I have highlighted the emotional reduction of Maya's character and added some aspects of cystic fibrosis that the graphic novel does not consider, such as recent medical developments in genetic medicine or the option of a lung transplant. My analysis has examined how Telgemeier's portrayal of cystic fibrosis is motivated by the needs of the narrative and reproduces pervasive tropes of inspiration and reductive characterization. As I have shown, *Ghosts* seems written with a nondisabled reader in mind who can marvel at Maya's strength and optimism or empathize with Cat's fear of losing her sister. Keeping in mind that *Ghosts* is a narrative for younger readers, which also tries to explain cystic fibrosis in an adequate manner, the narrative portrays many of Maya's treatments accurately and addresses some difficult emotions well. However, it does so mostly through the perspective of an older sister. While applauding the effort to make my disease known to a wider reading public, I would have wished for a deeper insight into Maya's perspective, since it is still far too rare that people with disabilities or chronic illnesses take center stage in narratives about their lives.

Born slightly before the discovery of the CF gene in 1989 and with the hope of genetic treatment and a longer life expectancy ahead (cf. Schubert, 268f.), I have grown up with a different, more hopeful perspective on cystic fibrosis than the one portrayed in *Ghosts*. As a disability studies scholar, aware of the few fictional portrayals of cystic fibrosis and of the impact that these representations may have on real-life ideas about people with chronic illnesses or disabilities, I would certainly have wished for a less bleak and more realistic depiction of the disease.

Ideally, more of today's illness narratives would follow Arthur Frank's, who writes: »Those who have been objects of other reports are now telling their own stories. As they do so, they define the ethic of our times: an ethic of voice, affording each a right to speak her own truth, in her own words« (Frank, xxxi). Until then, as pointed out above, disability studies has to try and restore some of the perspectives that are silenced, forgotten or overlooked in these narratives. I have tried to do so by integrating my thoughts and emotions as a cystic fibrosis patient into my scholarly analysis, speaking from the position of an ›affected scholar‹.

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- 1] ›Crip‹, similar to ›queer‹ is a derogatory term that was reclaimed by activists to connote a positive, disability pride-based identity that at the same time pinpoints the continued exclusion of people with disabilities (McRuer, 19). When Kafer uses ›crip‹, she indicates that the problem she refers to is part of the disability activism and studies community.
- 2] That is, if one has the choice to pass as non-disabled, which, of course, not all people with disabilities have.
- 3] More detailed information about cystic fibrosis can be found at cff.org (US) and muko.info (GER).
- 4] Brad Dell (a. n. pag.) lists a few of the existing depictions, among them also Telgemeier's graphic novel, and the fictional character Emma Decody in the thriller series BATES MOTEL. The medical drama series GREY'S ANATOMY (maybe less surprisingly) also features several patient-characters with CF. While a few pathographies ((auto)biographical illness narratives) on CF are available, fiction featuring the disease is even rarer, with a few children and young adult novels appearing only in the last two years, among them *Caleb and Kit* (Beth Vrabel, 2017), *Dead Girls Society* (Michelle Kryes, 2016) and *No One dies in the Garden of Syn* (Michael Seidelmann, 2016).
- 5] Other than *Ghosts*, three other comics deal with cystic fibrosis but neither tells a longer narrative with a cystic fibrosis-patient protagonist. *Carriers. A Webcomic on Health, Luck and Life* (Lauren A. Weinstein, 2014), is a graphic memoir that details the fears of a pregnant woman that her unborn child could have cystic fibrosis. Andrew Godfrey's *The CF Diaries* (2011) also provides an autobiographical look at living with CF. *508. A Digital Comic Book for Children with Cystic Fibrosis* (Wade Wooley & Sean Moffat, n. dat.) depicts a young CF-patient, Wesley, who imagines his chest physical therapy as a space adventure and was explicitly written with the aim to »inspire and empower children with cystic fibrosis« (amazon.com).
- 6] Telgemeier uses yellow speech bubbles, sometimes with red text, to indicate high volume.
- 7] High-Frequency Chest Wall Oscillation, colloquially called the ›vest‹, is a common breathing treatment for cystic fibrosis, used mainly in the United States. The technique »involves an inflatable vest that is attached to a machine. The machine mechanically performs chest physical therapy by vibrating at a high frequency. The vest vibrates the chest to loosen and thin mucus. Every five minutes, the person stops the machine and coughs or huffs« (CFF c).

- 8] Actually, Cat might well be a carrier of the CF gene and have the risk of passing on the disease to her children. This aspect is not mentioned in the narrative but troubles the clear-cut distinction between health and illness that the comic represents.
- 9] This reading is supported by a drawing of a poster in Maya's room that very closely resembles the Disney princesses Elsa and Anna (115).
- 10] La Calavera Catrina, the figure of female skeleton with a grand hat, has become a central icon of the Mexican Day of the Dead-celebration (BBC, n. pag.). The figure was originally created by cartoonist José Guadalupe Posada (1852-1913) and was later included in Diego Rivera's famous mural *Sueño de una tarde de domingo en la Alameda* (1948) and adapted in Tim Burton's *CORPSE BRIDE* (2005) and has gained wide popularity, especially as a Day of the Dead-costume (ibid.).
- 11] »Narrative prosthesis« is a term coined by David T. Mitchell and Sharon Snyder (2000) and describes, in short, how authors often tend to use a disability as a device for characterization: »[I]n stories about characters with disabilities, an underlying issue is always whether their disability is the foundation of character itself« (6).