

BOOK REVIEW

Coming to terms with 'slow living' in crip time: Graphic novels on chronic illness

S MAHALAKSHMI, SHUBHA RANGANATHAN

Michael Towers, *Chronic Fatigue Superhero: The Hero with ME/CFS - POTS - FIBROMYALGIA Etc Etc...* (M. Towers, Illus.). Thorpe-Bowker Identifier Services Australia, 2022, 94 pages, \$ 21.95 (paperback), ISBN: 9780645410013.

And

Sarah Winifred Searle, *Sincerely, Harriet*. Graphic universe, 2019, 176 pages, INR 2144.94 (paperback), ISBN: 9781541545298.

The last few years have seen a surge in first-person accounts by people experiencing chronic illness and disability, whether in the form of autobiographies, memoirs, or graphic books. Additionally, people experiencing chronic illness and disability are chronicling their experiences in blogs and social media.* Graphic medicine literature is replete with graphic novels and comics on a range of conditions and disabilities. This piece reviews two such recent works that stand out for their remarkable insights despite their simplicity.

Chronic Fatigue Superhero by Michael Towers is a short yet crisp peek into the life of an individual experiencing Chronic Fatigue Syndrome (CFS) with Postural Tachycardia Syndrome (POTS). The main protagonist, a CFS superhero, is an oxymoron superhero, one who wants to be there for everyone in need, but then gets diagnosed with chronic fatigue syndrome and needs support himself. With his vulnerabilities and everyday struggles, this protagonist pushes us to think about the "normal" and the "heroic" in creative ways. For his strength is achieved not *despite* his disability, but *because* of it. The fact that his super mobile is his wheelchair and his sidekick is his caregiver reflects the central role played by disability in the

superhero narrative.

The book starts on an interesting note, with the chronic fatigue superhero emerging after 13 hours of rest since the last rescue. Disability studies scholarship has argued for an appreciation and celebration of crip time — the concept that living with disability makes one experience time differently — one that acknowledges the ebbs and flows of different body-minds. For Kafer, crip time is validating, for "rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds" [1]. Towers explicates this flexible approach to time by chronicling the everyday struggles that this superhero faces with a comical spin. For this superhero, mundane tasks such as bending to pick up something or standing in the shower demand superhuman strength, thereby offering a critical take on notions of functionality and the "normal."

Towers has taken up the task of explaining the symptoms and daily struggles of a person diagnosed with CFS with a sardonic spin. The foreword mentions his preference for stick figures and minimalistic colours as that was all he could draw on days of intense pain. Towers uses the book to throw light on how even the smallest tasks such as bending to pick up something could mean not being able to get back up. There are quite a few strips that take a dig at the "super-specialists" that populate the industry of chronic illness, and the endless expensive investigations and medicines that are employed with no results to show. This again inverts the superhero trope, for it is the patient, rather than the doctor, that is portrayed as the superhero.

The book is a starter's guide for anyone who wants to understand what it means to have Chronic Fatigue Syndrome. Representing the fragmentation caused by chronic illness, the book uses separate pages to depict individual events and does not use a continuous mode to tell a story. This allows the author more room to cover various instances of daily struggles without being burdened by having to tell a sequential story with a positive twist. Instead, the book has interesting parts such as a puzzle section that represents the experience of brain fog. This is a simple yet powerful way to convey how during intense episodes of CFS, even the simplest things might take "superhero" efforts to complete.

Several questions come up for the reader who gets through this book. One wonders about the endless doctors' visits, constant care, and "floating" at a point where time

Authors: **S Mahalakshmi** (corresponding author — la17resch11003@iith.ac.in), Research Scholar, Department of Liberal Arts, Indian Institute of Technology Hyderabad, INDIA; **Shubha Ranganathan** (shubha@la.iith.ac.in), Associate Professor, Department of Liberal Arts, Indian Institute of Technology Hyderabad, INDIA.

To cite: Mahalakshmi S, Ranganathan S. Coming to terms with 'slow living' in crip time: Graphic novels on chronic illness. *Indian J Med Ethics*. 2023 Oct-Dec; 8(4) NS: 338-339. DOI: 10.20529/IJME.2023.023

Published online first on March 10, 2023.

Manuscript Editor: Sanjay A Pai

Copyright and license

© *Indian Journal of Medical Ethics* 2023: Open Access and Distributed under the Creative Commons license (CC BY-NC-ND 4.0), which permits only non-commercial and non-modified sharing in any medium, provided the original author(s) and source are credited.

transcends its limits. Towers has an active Instagram account followed by thousands in which he shares his experiences and celebrates little successes. A recent post about a fishing trip titled “celebrate every win” displayed a few pictures of the author with a small smile holding up the fish he had caught on a sunny day. The build-up to this photo, though, was a far more complex story. He was helped by his disability social worker to lie on the grass. After catching a few fish, he felt so dizzy and “sick beyond belief” that he had to be brought home and the next three days were spent in bed. This incident elucidates “crip time.” We are left to grapple with questions such as: in a world driven by ambition and the rat-race, where does it leave those whose entire strength is summoned to get through the day? Where do we place the responsibility of care — not only for the present but also for the future?

The book ends on a rather philosophical note that encourages everyone to find strength from within, especially when they do not find any around them. Everyone is their own superhero.

The second book *Sincerely, Harriet* by Sarah Searle is written from the perspective of a young tween girl who experiences a home-bound summer due to chronic illness. While her friends are away at a summer camp, she is confined to her home in Chicago. Having recently moved into the big city from a smaller town, and with both her parents out working during the day, Harriet has mostly herself for company during the day. Eventually, she learns to entertain herself with her imagination, spinning fantasies about ordinary events, whether it is in terms of seeing an ordinary mailman as sinister or imagining the floor above her as haunted. All the while, she continues to write postcards to her friends at camp, postcards that sadly draw no replies.

Things take a slightly different turn when Harriet begins to spend time with her elderly neighbour who lives in the floor below. While she doesn't particularly take to Pearl initially, over time, Harriet opens up to the possibilities that Pearl lays before her, particularly, the power of stories. The relationship between Pearl and Harriet is mediated through narrative, for Pearl introduces Harriet to books in her house and tries to get her to start the practice of reading. That Harriet has been exploring the world of books is already suggested by her subscription to teen magazines/comics in the hope of finding relief from her boredom. While Harriet is initially cynical, eventually, she opens up to the world of stories. And therein lies her escape and meaning, as she learns that books can provide company and entertainment in the absence of other options.

Searle's *Sincerely Harriet* has a way of aptly depicting the slowness of time when one is dealing with chronic illness and disability. As someone who has lived with chronic illnesses

over several years, and represented these in several memoirs and autobiographies in comic form, Searle has fine-tuned the skill of telling stories about mundane, everyday events. As with several books on chronic illness and disability, we see a renewed emphasis on the study of the everyday, which has a long history in sociology [2,3]. And like works in this genre, the book leaves the reader with a feeling of hope, hinting that meaning and contentment can be found in the little successes in everyday life with chronic illness. And therein lies the value of graphic books on chronic illness/disability: they illustrate the value of a different kind of ethic of work and productivity, an ethic that takes seriously the importance of crip time and slowness [4]. For these two books are written by authors who do not just tolerate their disabilities but embrace them.

One facet missing from both works is any representation of the systemic or structural factors in disability and chronic illness. As Linton has articulated, disability studies perspectives are marked out by their emphasis on the socio-political and structural dimensions of disability, as opposed to interventionist approaches that seek to “fix” or cure disability [5]. From the former perspective, disablement is more a consequence of structural barriers and non-inclusive conditions than a result of bodily or mental impairment. With increasing life expectancies and advanced medical care, we are likely to see more and more people experiencing chronic conditions, where being able-bodied is only temporary and disability becomes a fact of human experience for all persons. In her classic article recounting her experience with suddenly encountering a chronic disabling condition, Susan Wendell powerfully emphasised that in many cases, given the limits of medicine, attempting to “fix” disability might be more harmful than embracing one's diversity and learning to work with it [6]. It would have been good to see more allusions to these structural processes of disablement in both books, even as they stand strong as lived accounts of chronic illness and disability.

***Note:** See, for example, this list of “15 people with chronic illness you should be following on Instagram”.

References

1. Kafer A. *Feminist, Queer, Crip*. Indiana University Press; 2013.
2. de Certeau M. *The Practice of Everyday Life*. USA: University of California Press; 1984.
3. Lefebvre H. *Critique of Everyday Life*. Vol. 1. London: Verso; 1991.
4. Ranganathan S. “Slow research” in the time of Covid-19. *Indian J Med Ethics*. 2020 Jul-Sep;5(3):212–4. <https://doi.org/10.20529/IJME.2020.072>
5. Linton S. Disability Studies/Not Disability Studies. *Disabil Soc*. 1998;13(4):525–39. <https://doi.org/10.1080/09687599826588>
6. Wendell S. Toward a Feminist Theory of Disability. *Hypatia*. 1989 Summer;4(2):104–24. <https://doi.org/10.1111/j.1527-2001.1989.tb00576.x>