Review Article

Why should speech-language pathologists read graphic novels? A commentary on humanities as a pathway to improving patient-centred care

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Abstract. Like all who work in medical or allied health professions, speech-language pathologists would benefit from supplementing their learning with humanities education, as it can help to improve diagnostic skills and to develop empathy. Graphic novels on illness and disease, conceived of by those in the medical humanities as "graphic medicine," have an appeal for their brevity and association with humour, and for their ability to express complex thoughts and feelings through a medium that is both visual and literary. As such, they serve as an ideal resource for deepening one's understanding of how disorders and diseases are experienced by patients and their caregivers and for helping student clinicians, therapists, and researchers recognize their shared humanity with patients and study participants. In this article, I expand on these ideas and, in order to demonstrate the benefit of closely reading graphic novels from a speech-pathology perspective, I offer my own analysis of *Tangles: A Story of Alzheimer's, My Mother, and Me* by Sarah Leavitt (2012).

Keywords: Graphic medicine, dementia, speech-language pathology, humanities

Getting a foundation in the humanities means, for medical practitioners and allied health workers, learning to think critically about their relationship with their patients or clients and to engage with them respectfully and ethically as humans with unique histories, worldviews, and cultures (Crawford et al., 2010, 2015; Wald et al., 2019; Bionolo et al., 2019; Dumitru, 2019; Rabinowitz, 2021; Robinson et al., 2016). A number of medical humanities departments

and programs have been established, giving medical students a solid underpinning in humanities to help them keep their practice patient-centred. (e.g., *Other Health Humanities Programs* at med.standford.edu lists about 30, not including Stanford University [Stanford Health]). Wald et al. noted, "A recent American Association of Medical Colleges (AAMC) survey found that the majority of U.S. and Canadian medical schools have included MH [Medical Humanities] programs" (2019, p. 493). However, there has yet to be a strong association formed between speech-language pathology and the humanities. In their article "Spotlight on: Humanities in Speech and Language Therapy," Walsh and Mallinson (2022) argued that "an awareness of the diverse range of

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other learning resources and opportunities afforded by engaging with the arts and humanities [...] can open a world that complements the knowledge and skill of our sometimes restricted or constrained world of speech and language therapy" (section 1). As a student of speech-language pathology with a PhD in Spanish literature, I have found myself situated at the intersection of allied health and the humanities, and as such, drawn to medical/health humanities approaches like graphic medicine. Comics, or graphic novels, featured and reviewed on websites like graphicmedicine.org and the National Institute of Health's National Library of Medicine (NIH's NLM) cover a variety of topics, including COVID-19, obesity, cancer, loss, aging, anxiety, alcohol addiction, and hepatitis C, as well as topics relevant to speechlanguage pathology, such as autism, cerebral palsy, deafness, dementia, Parkinson's disease, and TBI. Focusing here on dementia as an example, I consider how, like any health professional, current and future speech-language pathologists (SLPs) can benefit from the new interdisciplinary field of graphic medicine, that is, from reading and analysing graphic narratives that deal with pathologies, with the goal of gaining insight into the patients' and their families' perspectives. In what follows, I describe a humanities approach as a correlate to the biopsychosocial and social models; I explain what graphic medicine is and expand on how it is beneficial; I suggest ways the reading of graphic novels could be encouraged during pre-registration, undergraduate, or graduate-level studies; and finally, I discuss insights one graphic novel in particular, Tangles: A Story of Alzheimer's, My Mother, and Me by Sarah Leavitt (2012), offers to future and current clinicians. A brief annotated list of graphic novels on the topic of dementia is provided in an appendix.

While president of Harvard University, Drew Gilpin Faust said, "What the humanities teach [...] is that the correct description and analysis of human life is not a scientific affair" (Gilbert, 2016, para. 6). This is not to say, however, that this non-scientific discipline is incompatible with or naturally separate from the scientific (Robinson et al., 2016). Medical/health humanities unites them, bringing the human and humanity back into a field that had been stripped of it, a field where medical care had become, according to Borrell- Carrió et al., "dehumanizing" (2004, p. 577) and in the words of Rabinowitz "devoid of humanism" (2021, p. 1). Taking a humanities approach to speech-language pathology is a way of moving away from a purely medical model of disabil-

ity and disease, and as such can be seen as consonant with the social model¹ and the biopsychosocial model.² These models have sought to prioritize patient involvement in treatment design, when treatment is wanted (Byng & Duchan, 2005). The overlap between the social model and the humanities, specifically the relatively recent interest in graphic novels, is made evident by the fact that the journals The Journal of Medical Humanities and Medical Humanities have published articles on graphic novels that use a social model theoretical framework, for example, Squier's "So Long as They Grow Out of It: Comics, the Discourse of Developmental Normalcy, and Disability" (2008) and Gibson's "Graphic Illustration of Impairment: Science Fiction, Transmetropolitan and the Social Model of Disability" (2020). Practitioners interested in pursuing a social model of care are told, "Listening to and engaging openly with the testimony of people with impairments is important" (Goering, 2015). It is important because "within the social model, people with disabilities [and we could add diseases, disorders, or impairments] are seen as experts in their own conditions" (Byng & Duchan, 2005). Since graphic novels are a source of both patient and caregiver testimony, they should be looked to as additional sources for broadening one's understanding of the patient perspective.

Some might be hesitant to spend their limited time engaging with something as "juvenile" as comics, but as Chute explained in *Why Comics?: From Underground to Everywhere*, comics (her preferred term for the alternative "graphic novel") is not a genre, but a medium (2017, p. 2). Like film or novels, comics can be directed at any age group and tackle any topic; the medium is not in itself either low-brow or highbrow (Chute, 2017). Take, for example, Art Spiegelman's Pulitzer-prize winning *Maus: A Survivor's Tale* (1995) about the holocaust, or the *March* trilogy (2013, 2015, 2016) about the civil

¹The social model, coming out of disability studies and with its roots in the social sciences (Mullaney, 2019, para. 6), argues that that which disables a person lies outside of that person rather than within their impaired body, that is, their functioning (Goering, 2015)

²The biopsychosocial model, which led to the World Health Organization's International Classification and Functioning, Disability and Health (Van de Velde et al., 2016), maintains that a person ought not to be viewed as just a body but as a body and mind (i.e., a body subjectively experienced) embedded in a social system (Borrell-Carrió et al., 2004), and that "both the person and the illness" need to be considered "in the reasoning process of the healthcare professional" (Van de Velde et al., 2016).

rights movement, co-authored by John Lewis and Andrew Aydin and illustrated by Nate Powell. Physician Ian Williams coined the term "graphic medicine" in 2007 when he started a website to compile comics with medical content (Czerwiec et al., 2015). He had been preceded and no doubt inspired by Charon's 2001 coining of the phrase "narrative medicine," by which she meant the application of the skills used in closely reading narratives to the analysis of patient-practitioner interactions (Charon, 2001). Charon maintained, "From the humanities, and especially literary studies, physicians can learn how to perform the narrative aspects of their practice with new effectiveness" (2001, p. 1898). As noted above, the patient's participation in the exchange with the practitioner has been likened to testimony; Charon reflected that the practitioner's role was to "bear witness" (2001, p. 1899). She observed that medical students and doctors were increasingly turning to "the humanities, especially literature, to grow in their personal understanding of illness" (Charon, 2001). To clarify what he meant by the phrase, Williams wrote and published in 2015 the Graphic Medicine Manifesto, along with Czerwiec, Merrill Squier, Green, Myers, and Smith, all of them professors and/or healthcare professionals. In the manifesto, they explained that they considered graphic medicine to be a valuable tool for educating health professionals, as well as a new "area of interdisciplinary academic study" (Czerwiec et al., 2015), and they described its purpose as, in essence, helping practitioners put the patient first. Graphic narratives present many and varied depictions of, and voices and perspectives on, disorders, illness, and healthcare, and reading them helps medical practitioners develop empathy (Myers et al., 2019; see also Graham et al., 2016 and Wald et al., 2019, on the ability of medical humanities to foster empathy, and Charon, 2001, on the ability of narrative medicine to do the same). As Nickerson observed in a 2018 article in Canadian Medical Association Journal, "Scientific medicine determines which facts, disease concepts or medical treatments are right or wrong. Graphic medicine, on the other hand, shows how patients and caregivers are complex and human" (p. E368). Graphic narratives are a valid tool for teaching students to be keen observers because they require not just "verbal literacy" but "visual literacy" as well (Chute, 2017), and learning to "read" visual art has been shown to improve the diagnostic skills of medical students (Doley, 2001; Naghshineh et al., 2008). Green and Myers (2010) explained,

To read a comic effectively, you must understand not only what is overtly seen and said but also what is implied. This is because much of the action takes place outside the boundaries of comic panels in the blank space known as the gutter. Thus, readers of comics, like doctors in the exam room, must determine meaning by inferring what happens out of sight and without words (p. 576).

On the other hand, although reading graphic narratives might on some level be considered challenging, there is, as Green and Myers themselves acknowledged, research that shows that combining image with text improves comprehension and strengthens connections between new and previously learned information (2010, p. 576). For this reason, graphic narratives can be considered a good tool not only for SLPs to learn more about their clients, but for them to use *with* their clients, when appropriate. *Aliceheimer's* author Dana Walrath (2016) in fact noted that she chose this medium because, through her experience caring for her mother, who had Alzheimer's, she realized it was "a medium that someone with dementia could access" (p. 5).

For such a thing as graphic medicine to exist there must be many comics with medical content, and indeed there are a plethora of such books and webcomics. Because they are so abundant, Chute (2017) devoted an entire chapter of Why Comics? to illness and disability comics, where she explained the appeal of this medium for such difficult topics: "Stories about illness and disability use the showand-tell aspect of comics so basic to its hybrid form to reveal hard-to-convey truths about sickness or ability" (p. 240). The popularity of graphic medicine as a supplement to traditional medical and health education has grown not just in the United States, but internationally. Graphic medicine.org, in English, provides links to similar resources whose developers come from Spain, Germany, France, and Japan. Many SLPs are concerned with educating themselves about their culturally and linguistically diverse clients, and since several graphic novels not originally written in English that fall under the graphic medicine umbrella have been translated (e.g., Wrinkles [Roca, 2007] and Little Josephine [Villieu, 2012] on dementia, A Chance [Durán & Giner Bou, 2021] on cerebral palsy, and Maria and Me: A Father, a Daughter, and Autism [Gallardo, 2014] on autism), they can be looked to as another source of knowledge about those clients, as a window into not only the patient perspective of the disorder or illness, but also their patient's culture.

The act of engaging with graphic novels could also serve as an antidote to a current tendency to conflate "patients" or "clients" with "customers," and to reduce the health system to a market with "customers" and medical professionals on opposite sides of the counter. Concomitant with the move toward emphasizing "person-centred care," there has been a shift toward referring to patients or clients as "consumers" (Gusmano et al., 2019; Weil, 2019), and as Gusmano et al. (2019) argued, such a shift could be dangerous: "It seems reasonable to anticipate that as the consumer metaphor grows, physicians' authority in these kinds of cases could erode to the point where they may become technicians doing what they are asked to do, but doing so against their own consciences" (p. 372). It is easy to dismiss this critique if one considers the reference to clients/patients as consumers/customers a simple and reasonable recognition of the fact that patients pay for speech-language services either out of pocket or through their insurance and thus are "consuming." However, the use of this language serves to emphasize the monetary exchange involved in the relationship between patient and SLP, which in turn can drive patients to perhaps feel they can demand certain services and clinicians to feel impelled to provide them, even if they do not deem them to be in a patient's best interest. Contemplating graphic novels on dementia can not only help shift medical SLPs' focus on purely scientific dementia-causing diseases back to the person with the disease, but also help them empathize with the patients and their families and see them as primarily humans, rather than as consumers of their services.

As Myers (in comic form) stated in the Graphic Medicine Manifesto, "sometimes people's stories get lost altogether when they become patients in a complex healthcare maze" (Czerwiec et al., 2015). To prevent this, the authors teach their students using comics, among other art forms like poetry and fiction, to gain a different perspective on and understanding of others' stories. Walsh and Mallinson (2022) acknowledged that it may be hard to convince speech-language pathology students or professors to add medical humanities courses to their already heavy course- or workloads, and suggested that a humanities perspective could be incorporated informally, for example through "self-directed learning" or "tutor-guided activities" (section 2). Additionally, professors could encourage extracurricular book clubs, and, on their list of suggested readings on their syllabi, they could include books on pathologies discussed in class. Walsh and Mallinson (2022)

suggested reading or viewing "biographies and autobiographies, fiction and non-fiction, film and visual arts, or poetry and prose, for example" (section 4). Graphic novels should be included in this list, because as Walrath said, "they have the advantage of speed. Pictures compress narrative" (2016, p. 5). Also, they have already been curated for health practitioners on such websites as graphicmedicine.org and nlm.nih.org. A search for a particular pathology on graphicmedicine.org will give the interested SLP a place to start. When there is more than one graphic novel on a topic, the covers and titles are displayed and hyperlinked to synopses. On the page with the synopsis, links to libraries and booksellers are provided. SLPs can also look to the NIH NLM's online exhibit called Graphic Medicine: Ill-Conceived & Well Drawn! whose Exhibition Collection likewise features a number of titles hyperlinked to synopses, as well as individual pages and panels (NIH National Library of Medicine). Allied health professors who would like to develop a graphic medicine library at their college or university can point their librarians to Essential Graphic Medicine: An Annotated Bibliography, available on graphicmedicine.org (Graphic Medicine). Another resource is the NIH NLM's graphic medicine book club kits on a variety of health problems; however, as yet there is only one related to speech-language pathology, which is on aging and can be used by SLPs who work with the elderly. The book the NLM suggests is Roz Chast's Can't We Talk About Something More Pleasant? (winner of the National Book Critics Circle Award for Autobiography in 2015), which addresses hallucinations and memory loss and depicts a cognitive assessment test. Although these kits are only available to members in the North-eastern United States (Connecticut, Massachusetts, Maine, New Hampshire, New York, Rhode Island, and Vermont), the questions for discussion are provided free online (Noe).

There are numerous graphic novels available on the topic of dementia, and as the number of people with dementia and the popularity of graphic novels both continue to rise, there will surely be more. See Appendix I for a briefly annotated list of graphic novels specifically on (or touching on) dementia, listed in order of publication. In what follows, I include some observations based on my close reading of *Tangles*, one of the most popular graphic novels on dementia, in order to discover what sort of lessons can be gleaned and how they can enrich an SLP's education.

The *Graphic Medicine Manifesto* authors stated, "We believe those best positioned to represent illness

and caregiving are those living with it" (Czerwiec et al., 2015). It is, however, for obvious reasons, difficult for people with dementia to comment on their situation. Leavitt addressed this fact in her memoir Tangles, a non-fiction account of her mother Midge's decline due to early-onset Alzheimer's, by describing her failed effort to communicate with her mother about her end-of-life wishes (by then "it was too late" [2012, p 58]). The memoir is, as English professor Venkatesen and PhD scholar Peter suggested in an article published in Research and Humanities in Medical Education, another kind of graphic medicine "manifesto": "the memoir is a manifesto of a caregiver's challenges, pain and perseverance in making the last years of Midge's life lighter and easier" (2015, p. 56). Although the perspective of this graphic novel is mostly that of the daughter (qua caregiver), the reader does gain insight into what it is like to be the spouse of someone with dementia, as well as what it is like to have dementia. Leavitt communicated the latter through direct quotes, which are provided alongside simple black and white line drawings of her mother, which capture telling expressions. The book has three parts, and at the end of parts I and II, there are full-page single panels that show Leavitt's mother's progression from despondency to milder sorrow. A third panel in the middle of part III portrays her loss of words. The fact that these panels take up an entire page, compared to the typical ten to fifteen panels per page, makes them stand out from the rest of the narrative as encapsulated moments in Leavitt's mother's decline. They all express Midge's feelings about how she is doing, but at different times and stages in the disease. In the first panel, we see Midge frowning when she says, "I hate what's happening to me" (Leavitt, 2012). The reader can gather from this that she is aware of her decline and frustrated about it. In the second panel, representing a later period in her Alzheimer's, we see a disconnect between the mother's expressions and her words (Leavitt, 2012). She says things are "going quite sadly" (Leavitt, 2012) but her slight smile suggests acceptance or even contentedness. Her language, having moved from hate to sadness has become less extreme, suggesting a change in her attitude toward the disease. The third panel recounts a phone conversation during which, to express how she was feeling, Leavitt's mother held up her index finger and thumb (Leavitt, 2012). We can infer from this that she was no longer able to find the words to express how she felt, and/or that she did not understand that a gesture representing a quantity would not convey a feeling. A close reading such as

this can help reinforce what speech-language pathology students learn in the classroom about dementia, namely, that as it progresses, both mood and communicative ability change. In a classroom or book club setting, an analysis of these three panels could be part of a larger discussion of how the facial expressions of people with dementia can or should be interpreted, connecting perhaps with research by Lautenbacher et al. (2013) or Gola et al. (2017).

Tangles also helps the reader understand that people with Alzheimer's (especially in the early stages) are not the only ones who might be angry about the disease. Leavitt described the anger she herself felt not only toward the disease ("I was sick of her being sick," 2012, p. 73) but toward those who avoided her mother once she became ill ("It's too bad you didn't bother visiting while she was still alive!" 2012, p.124). Juxtaposed with this anger, perhaps somewhat surprisingly, are several humorous moments. For example, one series of panels recounts an unsuccessful interaction Midge had with a friend, which failed not (just) due to her inability to answer his questions, but because of the perceived inanity of those questions. Leavitt and her sister turned his style of conversing into a joke: "Is that a banana you're eating, Midge?" (2012, p. 96) became a running gag of asking for constant naming. Reading this series of panels can help speech-language pathology students understand the importance of learning what sorts of questions or comments might be best to avoid, when possible, while interacting with a person with dementia. As a lead-in to a classroom discussion on how to talk to people with dementia, a speech-language pathology professor could show just the page titled "Is That a Banana?" (Leavitt, 2012) before segueing to a discussion of research on the best evidencebased practice, such as the arguments in favour of yes/no questions (Kindell et al., 2017, referencing Lisa Mikesell). Such a discussion might include a reminder that even if something has been determined to be best practice, it might not be understood as such and might need to be part of counselling provided for caregivers. Ideally, the discussion would go further and delve into the question of how such a study was conceived and designed: Were patient and/or caregiver concerns and perspectives solicited?

The panel sequence depicting the running gag also highlights the power of and need for humour among caregivers. The purposes of graphic medicine include not only broadening education and empowering and giving voice to people with disorders or diseases and/or their family members or caregivers, but also, at

times, bringing joy, through humour, play or creativity. Walrath noted, "The caregivers for the estimated 44 million people with dementia globally are in desperate need of a laugh" (2016, p. 5). In Graphic Medicine Manifesto, Czerwiec and Williams converse in comic form, Williams noting that "comics are full of play" (Czerwiec et al., 2015) and Czerwiec recalling that "play was sometimes how we coped" (p. 17) when she worked as a nurse in an AIDS unit in the 1990s. The dominant moods and emotions evoked by the graphic novels and comics that I have come across that deal with dementia might be described, unsurprisingly, as grief, regret, or sorrow. But we see that this literary and visual medium also leaves room for humour, even when the topics are serious. For example, even though the webcomic published in 2013 Hyperbole and a Half by Allie Brosh deals with the author's depression and anxiety, the drawings can have a "comedic effect" ("Hyperbole and a Half" graphicmedicine.org). In Tangles, Leavitt, too, found ways to lighten the mood. For example, she devoted two, rare, full-page panels to scatological "jokes" her mother seemed to be in on. The fact that these panels are given the wider frame of a mostly blank page serves to make them stand out as, at least for Leavitt, significant moments. The first is called, in fact, "A Small Joke." Below this title, Leavitt wrote, "We were listening to Bob Marley, but I can't remember which song. Probably One Foundation or Positive Vibration" (2012, p. 64). Just under these lines, near a drawing of a smiling Midge it says, presumably quoting her, "Did he say constipation? Oh, excuse me!" (2012, p. 64). The second panel presents one of the happiest moments of the book and is given the title "Who Farted?" Here Leavitt wrote, "Mom, Dad, and I were in the kitchen. Hannah came in and said, 'Ew! Who farted?' Dad and I both denied it, and accused Hannah of doing it herself. This went on for a while, until Mom said in this sweet little voice, 'No, I think I did.' We laughed so hard then, all four of us." (2012, p. 99). In both panels, Midge's slightly raised eyebrows suggest that she still had some awareness that her behaviour should be considered slightly silly. She recognized that it is funny to confuse (or perhaps intentionally rhyme) "constipation" with "vibration," and that she perhaps ought to have been a little embarrassed to admit that she was the one who passed gas. This moment, made joyful in large part by the fact that Midge joins in the laughter, is made poignant when just a few pages later, Leavitt describes her mother's separation from the group: "We started talking about Mom right in front

of her all the time, since she didn't seem to notice" (2012, p. 108). Seeing these examples of a caregiver finding humour in the face of dementia could serve as a springboard, as it did for me, into the scientific body of research on humour and dementia and a complement to that research. (See for example Moos, 2011; Person & Hanssen, 2015; Vavilla, 2016.) Readers might also be inclined, after reading Tangles, to research hand clenching in people with Alzheimer's, since this is something Leavitt portrayed and specifically commented on (2012, p. 28). A question for the speech-language pathology classroom might be, is she clasping her hands, or is this the classic handwringing seen in patients with dementia? Or does this suggest that therapists should not always assume a patient holding his or her hands together is "wringing" them, and that we need to be keen observers to see if the patient is indeed anxious? In general, one can imagine how graphic novels on dementia, or any topic related to speech-language pathology, could either spur current or future SLPs to find related scientific literature, frame new research questions, or help reinforce pre-existing or newly acquired knowledge by providing a visual "coat hook" to hang

Although the loss of dignity associated with needing help in the bathroom can be difficult for both the person with dementia and their caregivers, Leavitt found levity even in these situations. In one series of panels, she portrayed for the reader the scene of her singing a song she had invented in her childhood to help her mother go to the bathroom: "Tinkle tinkle little pee! Coming swiftly out of me! Yellow like a big banana, so much like my sister Hannah! Oh Hannah has to pee! She holds her crotch and drinks some scotch! Oh Hannah has to pee!" (Leavitt, 2012). The scene she depicted of her mother taking a bath with her own faeces floating in the tub is not described as in any way humorous, but Leavitt was able to recognize that helping her mother get cleaned up gave her "a new strength" (2012, p. 60). Contrasting with this "dark" scene, Leavitt later in the book devoted a page to the "lighter" moments, reflecting, "After three or four years, Mom didn't know she was sick anymore. This meant that she was happier. She rarely cried or got angry" (2012, p. 108). Such moments include singing, humming, and even dancing in a graveyard. It is well known that people with dementia retain an emotional connection to music and that music can elicit memories, language, and behaviour (Hale & Marshall, 2020); in Leavitt's graphic novel, we see that the author and the rest of the immediate family

learned that using music helped with the activities of daily living, such as in the bathroom scene just described. As another example, Leavitt's father sang to his wife "to get her to take her pills or eat. 'Swallow the yellow brick pill! Swallow the yellow brick pill!" (2012, p. 109). Again, reading the panels and tiers (i.e., rows of panels) illustrating these moments can facilitate discussion and/or perhaps inspire treatment methods.

In sum, graphic novels can serve to highlight and reinforce lessons taught in speech-language pathology programs, such as, that one ought to keep the patient at the centre of care and that treatment ought to be individualized to the needs and preferences of the patient. Although such words—patient, centre, care, individualized—are frequently mentioned together in Communicative Disorders classrooms, courses, and literature, a more focused consideration of the patient's and therapists' shared humanity would serve to reinforce the lessons taught in pre-registration, undergraduate, and graduate programs, and encouraged in continuing education courses. With regard to dementia in particular, it can be harder to recognize the humanity of people with dementia when one has not known the person before they developed the dementia-causing disease. Reminiscing and creating memory books are common therapies used to help people with dementia (Woods et al., 2018; Moniz-Cook & Manthorpe, 2009), and there is the added benefit that such treatments work, as well, to help practitioners get to know the patient and to help them see them as having a history, not just a disease. Reading graphic novels, which can be easier for busy SLPs and other medical and allied health students and practitioners to work into their schedules than full-length novels, is another tool they can use to help them empathize with and see their patients as people. One final consideration is how graphic novels might inform not only the SLP's perspective but his or her choice of treatment. That is, graphic novels might also serve as inspiration for a different kind of memory book, such as one that collects some of the lighter and more humorous or poetic-language moments that occur in the midst of decline.

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Conflict of interest

The author has no conflicts of interest.

Supplementary material

The Appendix is available in the electronic version of this article: https://dx.doi.org/10.3233/ACS-220003.

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