

The contribution of autobiography and literature to the understanding of Tourette syndrome

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SUMMARY

Objective

Tourette syndrome (TS) is a neurodevelopmental condition characterised by the presence of multiple tics and often associated with co-morbid behavioural problems, such as obsessive-compulsive symptoms, attentional problems and affective dysregulation. First-person accounts of TS are particularly important to understand key features of subjective experiences related to tic expression and other aspects at the interface between neurology and psychiatry. We therefore set out to explore the role of modern literature and autobiography in portraying TS to the general public.

Methods

We reviewed the full-text of a representative sample of modern literary texts and autobiographies and critically appraised their contributions to the understanding of Tourette syndrome.

Results

The reviewed texts explored the experience of TS from a variety of literary perspectives and demonstrated the contribution of autobiographical accounts to understanding tics and the rich inner world of patients with TS.

Conclusions

Our findings highlight the importance of literary accounts (particularly if written from a first-person perspective) in providing education about potentially stigmatising conditions, such as TS.

Key words: Tourette syndrome, tics, autobiography, subjective experiences, behaviour

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Conflict of interest

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Introduction: Tourette syndrome and the purpose of patient narrative

Tourette syndrome (TS) is a neurodevelopmental condition characterised by multiple motor tics and at least one phonic tic¹. Tics are defined as repetitive, non-rhythmic and a-finalistic movements (e.g. blinking, grimacing, shoulder shrugging) or vocalisations (e.g. grunting, throat clearing, shouting) perceived as involuntary and associated with characteristic subjective experiences of urges to tic, also called sensory tics². TS is a chronic disorder with onset around the age of 6 and chronic course with waxing and waning severity across the lifespan³. Once thought to be a rare and somewhat bizarre medical curiosity, TS has been re-conceptualised by recent epidemiological studies as a relatively common neurological condition, affecting up to 1% of the general population, with different degrees of severity³. Co-morbid behavioural problems are present in about 90% of patients, with obsessive-compulsive symptoms and attention-deficit

and hyperactivity being most commonly reported and playing a significant role in the impact of TS on health-related quality of life⁴⁻⁶. The aetiopathological models of TS have undergone a paradigm shift between the beginning and the end of the last century, from Ferenczi's psychoanalytic observations on tics to modern biological models in which genetic factors play a central role³. Historically, TS has often been viewed in literature as "shorthand for concealed insanity or malevolence"⁷, but the place of this condition in non-medical literature reaffirms the value of the patient's own story⁸ and the importance of the patient as an individual⁹.

The meaning of patient narratives or autobiographical accounts has been thought to lie in providing the unique opportunity for patients to consider and approach their illness differently, and for the clinician, the means by which to treat the patient as a whole¹⁰. Making the 'whole' person matter more in modern clinical encounters is an important asset of these patient autobiographies or 'pathographies'¹¹. Such pathographies have had considerable historical importance at times when patients chose to communicate with their physicians via personal correspondence, a practice which characterised 18th century medicine¹². While doctors cannot experience the patient's illness with them, they can learn to look for those personal reactions which are an important part of patient narratives¹². Others have suggested that the benefits of these accounts can permeate right through to the very mind-set which doctors use in their communication, and that bringing mindfulness into their interactions can benefit themselves as well as their patients¹³. Using this kind of awareness and sense of empathy are skills which are in high demand in psychiatry given the emotional weight of the situations which psychiatrist and patient are part of⁸.

The benefits of these narratives are valuable in the understanding of TS, firstly in the description of the motor and phonic tics which characterise this condition. This paper will explore the experience of TS from a variety of perspectives and demonstrate the contribution of these accounts to understanding this condition and the rich inner world which we may be privileged to observe. The authors will then consider how comparisons can be made and the lessons which can be learned from published academic accounts, which are derived from a different part of the spectrum of style, form, and language.

Physical symptoms

In the first of these accounts, *Passing for Normal* by Amy Wilensky, the author inevitably provides some description of her tics¹⁴. However, the value to the reader lies in the language used to describe them and what they mean to Wilensky and others like her. She recalls:

I could feel the tension building in the joints and muscles of my shoulders, neck, torso, and arms, the half of my body that bears the brunt of most of my tics (p. 20). Here the physical symptoms are described almost like an assault on the body, which becomes a notable style of writing in this account¹⁵. Again, there is the reminder that symptoms such as motor tics do not just happen to the patient, but that they also have personal consequences and significance for them which should not be overlooked¹⁶. This added quality to the experience of tics is described by Wilensky:

Wrong movements are tics, motions with no point, black sheep cousins of the hand that reaches over the shoulder to scratch the back (p. 35).

This is reflected in the second account, *Twitch and Shout* by Lowell Handler¹⁷. Handler provides this added quality to his tics, describing how "*my Tourette was expressing itself*" (p. 31) and the variability in his symptoms by explaining that "*I never knew what form it would take, and when*" (p. 45). Here the tics are a wholly separate entity, and this relationship of the patient to their TS is an important second theme of these accounts.

A personal relationship

Doctors have been criticised for distancing themselves from their patients too easily¹⁶, and being primarily concerned with treatment¹⁸. The need to rediscover the importance of personal reactions to illness⁸ may benefit much from these autobiographical accounts¹⁹. The nature of a patient's personal relationship with their tics is described in Handler's account using rich visual imagery, which helps to promote understanding in those who are unfamiliar with the condition²⁰:

If I could come to grips with some elusive inner demon that was strangling me, I thought, I would be able to imagine myself miraculously "cured". If I could solve my problems, then my calmer, more "normal" self would emerge as if from a cocoon (p. 33).

Thus, while Handler gives a visual representation to his tics, Wilensky puts a personal distance between herself and her TS, viewing her tics as "*characteristics of somebody else: a casual acquaintance, a friend of a friend*" (p. 14). Literature therefore demonstrates to the reader that there can be a complex relationship between individuals and their TS, *cautioning against oversimplifying this dynamic relationship and preventing to the creation of false assumptions*.

False assumptions

Wilensky wrestles with the idea that her tics may define her as much as any other unique physical characteristic:

Eliminating them with the pop of a pill was an eradication of my very soul, a self-inflicted stab wound to the

integrity of my character, the very make-up of my molecules (p. 161).

Through this powerful description, Wilensky demonstrates one of the key values of such autobiographies – their ability to bring the condition to the very centre of one's personal identity and underline its importance to the experience of life¹¹.

The second assumption is that patients will necessarily find support groups beneficial, something which is contradicted in the accounts discussed here. When being confronted with a spectrum of severity within support groups, both authors find it an uncomfortable experience to contemplate a worse future for themselves and their relationship with their TS. Handler recalls:

I was afraid that I might see how much worse the disorder could be, or that I would in fact become worse through this contact, as if Tourette were contagious, even to a Touretter (p. 46).

While Wilensky describes seeing another member of the group:

[It] was like stumbling upon a funhouse-mirror version of myself, like covering my eyes with my hands at the gruesome parts of a movie (p. 49).

Literature can be an important tool for clinicians simply through guarding against making assumptions about patients and preventing a paternalistic approach to managing conditions such as TS. While literature can help illustrating a patient-centred description of symptoms, how patients relate to them, and the assumptions which may be made, it can also make clinicians more aware of the consequences of formally diagnosing patients.

The formal diagnosis

The diagnosis for Wilensky is a pivotal part of her story, especially because of a difficult and misunderstood relationship with her father⁹. In a direct address to her father, she describes:

"I have a neurological disorder," I enunciated carefully. "You were wrong. I was right. I can't make myself stop" (p. 144).

Here the diagnosis empowers Wilensky to prove the assumptions of her father wrong with conviction, and therefore once again literature reminds the clinician that the diagnosis carries great significance. These accounts can be equally helpful as coping tools, using them to aid understanding from others' perspectives, a process termed 'contextualisation'¹⁸. Moreover, it could be argued that from a philosophical perspective certain literary accounts can save the patient's own moral identity²¹. While the diagnosis was equally cathartic for Handler, giving sense to an oftentimes bewildering past, his cautionary note was that "I began to see things in terms of 'them' and 'us' (p. 47). Handler's account could be beneficial for clinicians as an example of how

labels can force patients into expected categories and ultimately lead them to lead less fulfilled lives²⁰. In addition to the value the diagnosis holds for the patient, both authors also demonstrate how the diagnosis leads to a sense of ownership over the condition (and empowerment), to the point that they are presenting the facts and the experience of having TS to the reader. Wilensky achieves this and shows a desire to educate the reader themselves. Again, like Handler, she resorts to visual imagery to communicate the experiences familiar to her:

Picture your skin as comprised of only nerve endings with no neutral ground; in this case, the barely discernible pat of a fingertip would send sensations vibrating through every atom in your body. Welcome to Tourette's (p. 26).

This type of autobiography, termed "didactic" where the main purpose is to inform¹¹, is a consistent model across these accounts, possibly due to the relatively poor public understanding of conditions like TS. However, the ways in which these narratives inform the reader are not always complementary to a straightforward clinician-patient relationship.

Self-medication

Handler describes his long-term reliance on a "self-prescribed regimen of pot and Prozac" (p. 127), a routine which contributed to the end of his marriage but which provided him "a sense of inebriation and wellbeing" (p. 120). Wilensky is much more experimental in her use of cannabis, leading her to a realisation which clinicians may find difficult to respond to. She recalls:

The pot, I knew, had rendered me me again, but it was a version of me I only faintly recognised now (p. 123).

The realisation that conditions such as TS can be managed – to some extent – by self-medication with substances of abuse leads to the creation of a complex relationship with the condition and therefore an important lesson for clinicians. The benefits both authors found from cannabis is important for clinical training, as it emphasises that patients *will not always make the same carefully regulated and informed decisions as those of the clinician, and that actions such as these should be anticipated rather than ignored. Having described the ways in which these literary autobiographies of TS can help in better understanding the condition, the reader and clinician must bear in mind some key criticisms of this narrative form which should not be overlooked.*

Limitations of autobiography

Firstly, it should be anticipated that some level of publication bias exists in the same way in non-medical literature as it does in evidence-based medicine. Facts on their own are insufficient to attract an audience, and

in the process of their transformation to become more appealing, we can lose the sense of intimacy and personal encounter with the author²². Secondly, there is an expectation in the nature of these accounts that the author undergoes a personal transformation and sense of resolution with the world²², both of which could be said of Wilensky and Handler's accounts. Moreover, neither of these criticisms could be said to be resolved by biographical over autobiographical accounts²³. Shapiro recently argued that the reader can come to a resolution, and since "the story of the thing is never the thing itself", being aware of the way that the narrative may have been affected is not necessarily an excessive compromise²³.

Secondly, these accounts can perhaps mislead individuals with conditions such as TS, into the belief that they too can have the same freedom as the author to express their experience and most exposed feelings to their clinician, when this is unlike the true nature of clinical consultations¹³. Given then that the reader may be being misled into the realism of these accounts, the use of fictional narratives could offer a helpful compromise.

Motherless Brooklyn, by Jonathan Lethem

Lethem's character, Lionel Essrog, finds himself at the centre of a murder mystery which forms a chaotic side-line to his experience of TS²⁴. Lethem, like Handler, uses rich visual imagery to communicate Lionel's internal struggle, as reflected in the use of "cultural and physical metaphors and similes"²⁵. Here Lionel provides a way for the reader to access the experience of palilalia (self-repetition), a complex vocal tic associated with TS since its very first description by Georges Gilles de la Tourette in 1885²:

My own name was the original verbal taffy, by now stretched to filament-thin threads that lay all over the floor of my echo-chamber skull. Slack, the flavour chewed out of it. (p. 7)

While there is a rather complex use of language to be found in this account, Kravitz points out the plain and colloquial language used to describe Lionel and his appearance to the world. When he describes those people who have labelled him as 'crazy', he is demonstrating the cultural influences on his identity²⁵. However, Lethem's character also toys with cultural references, asking the reader: "*If a Touretter curses in the woods and there's nobody to hear does he make a sound?*" (p. 10). Through this observation and others, Lionel challenges the culture around him and indeed he is able to observe life in a way that others are not able to: *Tourette's teaches you what people will ignore and forget, teaches you to see the reality-knitting mechanism people employ to tuck away the intolerable, the incongruous, the disruptive- it teaches you this because you're the one lobbing the intolerable, the incongruous, the disruptive their way* (p. 43).

In fact, Lionel achieves this by assimilating the identity of a "freak", rather than ignoring it, feeling that to be otherwise would be to "dodge your destiny": this attitude inevitably leads to Lionel becoming "Overt Freak Supreme" (p. 68). Awarding himself this accolade is a powerful representation of his constant clashing with culture.

However, despite Lethem's inventiveness with language, Lionel's character is ultimately not supported by the story which surrounds it, calling into question any added benefit from writing a non fictional account in this style²⁰. Indeed there are occasions where Lethem's use of language distances the readers rather than bringing them closer to a genuine understanding of TS. Through his constant vocal tics, Lionel informs the reader:

I collected words, treasured them like a drooling sadistic captor, bending them, melting them down, filing off their edges, stacking them into teetering piles, before release I translated them into physical performance, manic choreography (p. 47).

If this style, in contrast to Wilensky and Handler, is to be used, then a balance must be found between engaging the readers and excluding them, something which Lethem may not have achieved consistently. Having therefore considered what patient autobiographies and fictional accounts have to offer, a balanced exploration can be achieved by considering the contribution of academics who have documented their own experiences of TS.

Two contrasting academic accounts

Compared to literary accounts, academic accounts are less likely to be accessed by the general population, despite being often written in an adequately thought out and engaging style. The first of these accounts is provided by Dr Lance Turtle and demonstrates a far more formal style in writing about personal experiences of TS²⁶. This account sees the clash between formal and attempted informal elements, which means that it is more challenging to determine the intended audience. Turtle begins his account with the sub-heading "In the Beginning", providing the author with a quasi-Biblical reference which is at odds with the overall presentation of his experiences.

In contrast to the patient autobiographical narratives presented in this article, Turtle switches between the technical style of a medical history and linguistic registries which provide more of a personal insight into his subjective experiences. Perhaps the reason for this struggle is found in the words of the author: "*It is very hard for anyone who has never had a tic to know what it is like to tic*"²⁶. Again, it is more convincing that without being able to use colourful language, narratives published in this domain encounter greater difficulty in educating the lay audience.

However, there are consistent themes which are found also in the other narratives presented, such as the sensory urges to tic. Liking the feeling preceding the tic to an itch is described by Turtle: “*The relief is temporary, however, and, much like scratching a mosquito bite, having executed the tic the relief is very transient*”²⁶. Likewise, Lionel in Lethem’s account describes his urge to tic:

It’s an itch at first. Inconsequential. But that itch is soon a torrent behind a straining dam. Noah’s flood. That itch is my whole life (p. 2).

Similarly, just as Wilensky observed that her tics define her as much as any other physical characteristic, so Turtle also recognises the contribution that tics have made to himself. He challenges the reader:

This is how I am, tics and all, and if you don’t like it, tough.

Similarly, as was noted in Handler and Wilensky’s narratives, the diagnosis of TS is an important moment, particularly for Wilensky in challenging her father. For Turtle, the diagnosis ultimately endows a sense of belonging. He concludes his own narrative with the conclusion:

Everything has its place. Now I have my label of “TS”; I too have my place.

The second academic account, by Peter J. Hollenbeck, chooses to address the audience more directly and finds the difficult line between making the reader interested and alienated²⁸. Here the identity of the audience is much clearer: Hollenbeck is directing the narrative towards society in its broadest terms. He describes TS as “*largely a disease of the onlooker. When I tic, I am usually not the problem. You are*”²⁷.

Again, there is similarity in this context to its patient narrative counterpart. Hollenbeck echoes the same observation made by Lionel in Lethem’s narrative:

If I have a tic and there is no one there to mock me, is it a tic?

Hollenbeck even questions the existence of his TS if it is without an observer, and part of his challenge to the society around him lies in the fact that his tics go against the rules of order which society depends on. This is something which has been described as lying at the heart of how this condition is perceived, the patient as an unstoppable and frightening person⁸. Hollenbeck describes others’ reactions to his tics:

I was a disordered body in their field of view, and they could not resist the urge to establish order.

These influences lead to a second theme shared by Hollenbeck and Wilensky: given the way that TS is considered part of the self, in both accounts there is a strong sense of ownership over the condition in which the individuals are exhibitors, presenting the condition for the world. Hollenbeck observes:

Like all people afflicted with chronic disease, we Tourette sufferers become experts on our own condition.

Wilensky communicates the same principle through the style of language that has been noted previously:

Picture your skin as comprised of only nerve endings with no neutral ground; in this case, the barely discernible pat of a fingertip would send sensations vibrating through every atom in your body. Welcome to Tourette’s (p. 26).

Since there are these macroscopic differences and similarities between patient/fictional narratives and academic work, deciding on their contribution to the understanding of TS is not simple, and perhaps meaningless. The two latter authors are in the position of publishing among their peers and as such, the lay readers only benefit from as much as the author is prepared to give away of themselves. Hollenbeck provides a rather humble perception of the impact of his narrative:

Tourette is frustrating, annoying, occasionally humiliating, but it is hard to imagine others finding inspiration in my paltry battles.

If Hollenbeck describes the potential for inspiration from his published narrative as limited, it could be argued that this is a contribution which is mainly achieved in patient narratives¹¹ and therefore that the limitations described earlier are an acceptable cost for providing this inspiration.

Conclusions

Literature and autobiographical accounts have a great deal to offer to patients and clinicians, providing a unique platform from which to approach illness. The autobiographical accounts of TS described in this paper have demonstrated how literature can teach clinicians and lay readers valuable lessons in how patients relate to their symptoms and their complex interaction with the tic symptoms and the external observers. Within the narratives of TS presented here, readers are privileged to witness an interlinking and intricate world of language which is used to communicate several important key themes. Descriptions of the tics themselves, patient’s personal relationships to them, the meaning of the diagnosis, and the assumptions that may be made by clinicians, are all beneficial in helping to understand the narrative context of TS. However, the realism of these accounts can be called into question, meaning that the contributions of other forms of narrative must be considered. Unfortunately both fictional and published academic accounts seem to convey their own limitations, in addition to unique insights. Lethem’s account could be in danger of alienating its audience, while the stories of Turtle and Hollenbeck differ considerably in style and only provide as much benefit to the understanding of TS as the authors can afford to provide of themselves. TS as “largely a disease of the onlooker” will always have a

place within both patient autobiography and literature, but the ways in which they assist the reader in understanding the condition vary considerably and carry their own limitations. The role of education should not be underestimated, as the following semiserious lines epitomize: "I've just invented a new drug for Tourette syndrome!" "Will it stop people with Tourette syndrome having tics?" "No, it's an acceptance pill for everyone else". In the future, the contribution of other forms of

narrative can be fruitfully explored, including - perhaps surprisingly - the use of comics by patients, calling for an even more active participation from the reader²⁸. Finally, the novel *Motherless Brooklyn* has recently been adapted as a neo-noir crime film directed by Edward Norton. Cinema and television can usefully complement the role of novels, plays, and poems dealing with movement disorders in providing education about potentially stigmatising conditions^{29,30}.

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