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Research paper

Precision or narrative medicine? Child neurology needs both!

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ABSTRACT

Precision medicine aims to understand the mechanisms of diseases and to find treatments adapted to each individual or group of patients, on the basis of biological characteristics and environment. It uses new tools based on digital technologies. Narrative medicine was theorized, in the 2000s, as a reaction to the increasing technicality and the notion of a lack of human relations in care: It focuses on recognizing the essential place of the patient's experience of illness and life history in the diagnosis and management of diseases as well as in the training of caregivers.

These two opposite currents are rarely considered together. In fact, they have in common the basic principle that each patient is unique, and both are often more closely intertwined than we think, especially in the field of child neurology. Five case histories and discussions presented here aim to demonstrate that combining the precision approach with the narrative approach can improve the diagnosis, treatment, classification, and understanding of neurological conditions, as well as enhance the dialog with families and make teaching more meaningful. Not only rare diseases but common problems, such as paroxysmal events, pain, epilepsy, intellectual disability, and autism spectrum disorder, are addressed from both perspectives.

Introduction

Precision medicine has already made up the title of thousands of articles and conferences over the past 10 years, and the use of narration or storytelling is well known as a powerful communication tool for promoting products or ideas in any field of activity. What novelty can a pediatric neurologist then bring to these topics?

Precision and narration appear to be completely opposite trends in medicine, the former clearly being a matter of science and the latter being closer to humanities. In fact, both have in common the basic principle that each patient is unique, whether in his or her biological characteristics or life experience; and even if they are rarely addressed together by the same specialist, both are often more closely intertwined than we think, especially in the field of child neurology. To illustrate this and to demonstrate that combining the precision and narrative approaches is a necessity for a meaningful practice, I have devised a five-step itinerary: Each step begins with a case history and discusses different points of interest. Not only rare diseases but common problems, such as paroxysmal events, pain, epilepsy, intellectual disability, and autism spectrum disorder, are addressed from the precision and the narrative perspective, along with the insights from my career as a child neurologist in a university hospital.

Cases and discussion

Case 1

G., a 2.5-month-old baby boy, presented in 2002 with severe episodes of crying, associated with reddening of one or both buttocks, as if burned by hot water. These started at birth and were triggered by the passing of harder stool or rubbing the perineal area with a cloth. Only cold water could soothe the pain. The baby was otherwise fully healthy. Family history revealed that his mother, her own father, and a few other relatives living abroad had the same kind of excruciating pain attacks since childhood that they had hidden for years out of incomprehension and shame. Whenever the mother entered a new place, she would immediately look for a cold water tap, just in case.

Discussion

G.'s story is emblematic of a very rare disease called, at that time, "familial rectal pain syndrome." The family was enormously relieved by this diagnosis and agreed to participate in genetic research with 12 other families. Six years later, the discovery of a mutation in *SCN9A* was published [1] and the disease was relabeled "paroxysmal extreme pain disorder (PEPD)," at the request of a group of patients who found the original designation too stigmatizing. *SCN9A* encodes specific sodium channels called $Na_v1.7$ placed all along the afferent sensitive pain nerve fibers, from their terminal arborizations in the skin to their entry into the spinal cord; it is also found in the

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trigeminal and vagus nerve ganglia explaining other symptoms of the disease such as jaw pain and bradycardia with syncope. Later, PEPD mutations were shown to confer gain-of-function to $Na_v1.7$, while by contrast, loss-of-function leads to congenital anesthesia [2]. Gain-of-function mutations also lead to another pain phenotype, familial erythromelalgia: This manifests as episodes of burning pain with redness like in PEPD, but in the extremities, elicited by heat or activity and also relieved by cold, as in the case of G.'s family.

A few years later, the boy's mother consulted a colleague in adult neurology, who prescribed carbamazepine, pregabalin, and amitriptyline; none of these helped, so that he asked for the collaboration of an anesthesiologist and researcher specialized in pain. He inserted G.'s p.L1612P mutated $Na_v1.7$ channel in a cell culture: Gain-of-function was confirmed, but amitriptyline did not significantly modify its electrophysiological parameters compared to the wild type. Cold, however, did, as the family already found out, and this was published as a first cold-sensitive PEPD variant [3].

Such a clear genetic and biological model — gain-of-function corresponding to excess of pain, no function corresponding to absence of pain — encouraged scientists caught in the middle of the opiate crisis in the United States to look for the "painkiller of the future" by developing selective blockers of $Na_v1.7$. Large funds were raised and start-ups created, but unfortunately all these attempts failed [4]. Currently, trials to locally repress the expression of the $Na_v1.7$ channel in mouse models of chronic pain are underway, using new epigenomic engineering techniques: Long-lasting anesthesia was obtained when a repressor of $Na_v1.7$ transcription was injected by lumbar puncture via an adeno-associated virus, so that it specifically entered the sensory neurons of the mouse [5].

This story illustrates all the successive steps of a ***precision medicine approach:*** By definition, it aims to understand the molecular mechanisms of a disease and to find a treatment adapted to a person or a group of patients, based on biological characteristics — for instance, genetic and metabolic — but also on their environment. It involves the help of digital technologies — for instance, registries, data bases and biobanks — with connected monitoring and artificial intelligence algorithms.

In pediatric neurology, the diagnosis of severe epilepsies, abnormal movements, intellectual disability, and rare metabolic diseases has been revolutionized over the past decade by advances in imaging, genetics, and molecular biology. This has of course generated huge expectations about targeted and disease-modifying treatments [6,7]. But we have to admit that such an approach takes time and often comes up against unexpected obstacles. For patient G. and his family, blocking the transmission of pain signals in a seemingly simple and small nerve fiber is still a world away; and if this is difficult to do for the peripheral nerve, the more so it is for the brain!

For instance, in Dravet syndrome, a severe and refractory epilepsy of infancy, the journey to get to a first Phase 1–2 clinical trial of a treatment aimed at increasing gene transcription took 20 years: The culprit *SCN1A* mutations causing sodium channel loss-of-function in cortical inhibitory interneurons was indeed already identified in 2001 [8]. This should incite one to patience and humility, however optimistic one may be.

G.'s mother's accounts of her strategies to abort attacks using cold water, the reasons that led her to hide her pain attacks, and why she refused to give carbamazepine to her son are examples of a ***narrative medicine approach.*** The narrative medicine movement was created in the 2000s in New York, by Rita Charon, a physician with a PhD in literature, as a reaction to the dryness of an increasingly technical medicine: It aims at recognizing the patient's life story and experience of the illness in order to improve care, and also the training and teaching of healthcare staff by applying the tools of the human sciences [9]. Narrative medicine uses the study and production of detailed clinical histories and testimonials of patients, and Charon introduced it into the medical curriculum at Columbia University. She encouraged her students to write about their patients in a literary rather than a scientific language, and to reflect on their own history and the motivations of their professional choice. Since then, other universities have taken up such programs, and therapeutic writing and educational workshops have been created for patients. It also took 20 years until an editorial promoting the submission of articles with the narrative perspective appeared in *Pediatric Research* [10].

Case 2

E., a 14-year-old teenage girl, was having fainting spells accompanied by a feeling of "not being in herself anymore," occurring while running at the gym. Twice, her physical examination, performed after an episode was normal as was a standard electrocardiogram (ECG). She had a few episodes of migraines in the previous 18 months, but was otherwise healthy. Her pediatrician asked me whether this could be epilepsy. My answer was that focal seizures with impaired awareness and out-of-body feelings have indeed been reported, but that here, given the context of physical effort, the absolute priority was to rule out a cardiac cause with an exercise ECG; this test revealed ventricular tachycardia, possibly due to a rare potentially fatal disorder called "catecholaminergic polymorphic ventricular tachycardia." I thus never saw this teenager, but I asked my colleague if E. would agree to write about her experience. I received a page and a half of a precise and lively description from which I quote a short passage:

"I ran and ran. My feet and legs became heavier and heavier, but at the same time, I had this feeling of flying. Not flying like the chirping birds, but flying in the sense that I was not touching the ground anymore. This feeling of not really being in myself was pleasant. Then the colors that jumped to my eyes: especially the little white border around the lawn of the stadium... and suddenly nothing. Black hole..."

Discussion

Like E., adult patients who report on "out-of-body experiences" often have a pleasant feeling of leaving their body and flying upwards. This results from a failure of integration of visual, somatosensory, and labyrinthine perceptions in the parieto-temporal regions: causes are most often ischemic, such as in cardiac arrest, syncope, or migraine, by lack of irrigation of the vascular border zones located in these strategic regions. As for epilepsy, out-of-body experiences were reported in focal seizures with onset in the parieto-temporal areas due to lesions, mainly on the right hemisphere. These could also be provoked by local electrical stimulation during presurgical explorations, including in children [11].

Here, E.'s keywords — "I'm not in myself anymore" — and the context were decisive for the correct diagnosis and her narrative is a testimony rarely obtained in children. It reminds us vividly that reduced cerebral blood flow, due to a potentially fatal cardiac dysfunction, can mimic epilepsy.

Long before narrative medicine was theorized, pediatric neurologists knew and taught that obtaining the child's and parents' story, in their own words, was a critical step in making a diagnosis, especially of paroxysmal events. Of course, not everyone has storytelling skills, especially small children who struggle to put their feelings into words: drawings that they produce at the consultation, or from peers, can efficiently replace a story or encourage them to talk, for instance, when they suffer headaches [12]. Paper and pencils thus remain useful tools in the era of digital hospitals.

Case 3

Thomas and Matthieu are two brothers with intellectual disability, who initially presented with hypotonia and motor delay from

birth. They became known in French-speaking countries thanks to an autobiographical novel entitled *Où on va, Papa?* (*Where We Going, Daddy?*) written by their father, J. L. Fournier [13], also a film-maker and humorist. It received the Femina literary award in 2008, but caused controversy in the disability community, because its content was quite disruptive, full of black humor, and politically incorrect.

Here I translated a quote that explains the title:

"Since we got into the Camaro, Thomas, 10 years old, repeats as he does all the time: 'Where we going, daddy?' At first, I answer: 'We are going home.' A minute later, with the same candor, he asks the same question again, he doesn't print. At the tenth 'Where we going, daddy?' I don't answer anymore. I don't know where we are going anymore, my poor Thomas. We are going downhill, we are going straight into the wall. One handicapped child, then two, why not three? I didn't expect this. Where we going, daddy? We are taking the highway, on the wrong lane. We are going to Alaska, we will pet the bears, we will get devoured. . ." [13].

Thomas and Matthieu's mother, divorced from the author, obviously did not have the same point of view: She describes her sons very differently on a protest website, making one wonder if they are the same children.[1]

Discussion

It is clear that each person's experience of illness or disability is unique, but scholars who studied the stories of patients and families have found that they follow common narrative patterns specific to illness. They are about battles against evil, against an incompetent or insensitive medical system, about the search for meaning, about redemption through suffering. They reflect our Christian and performance-oriented culture, which requires us to "succeed in our illness." By going against these models, Fournier has shocked and one may wonder whether he would still be published and awarded today.

Is there room here for precision medicine? Family pictures of Thomas on his mother's website show an impressive physical transformation between the ages of 5 and 45 years: She describes it as "an accelerated aging and decay process." With today's means, we may find a genetic and metabolic key to this remarkable evolution and his parents may at last find some relief in an explanation. Better than their father's comment: "Perhaps 'genetic' is the academic term for 'bad luck'. . ." [13].

Case 4

Lia is a girl, born in 1982, who started having refractory epileptic seizures at 3 months of age. She was born in California to Hmong immigrant parents, an ancient, fiercely independent people from the mountains of Laos. They became allied with the Americans against the communist forces that wanted to invade their territory, at the time of the Vietnam War.

For the doctors, Lia had generalized, but also sometimes one-sided seizures and status epilepticus (SE), often triggered by fever. Development was initially considered normal, but she became increasingly delayed and difficult in her behavior. Between the ages of 8 months and 4.5 years, she was admitted 16 times to the emergency room and was seen more than 100 times in the outpatient clinic. She received many different antiseizure medications. Lennox–Gastaut syndrome was diagnosed by a renowned pediatric neurologist.

For the parents, Lia's soul had fled her body. The disease was dreadful but may herald a destiny as a shaman, a highly venerated position. To recapture her spirit, animal sacrifices were necessary, as were herbs, and to apply amulets and suction cups.

The language barrier was massive, translators were rare and often not qualified. The parents did not comply to treatment as prescribed and instead did what they believed was good. The child was finally placed in foster care.

At the age of 4.5 years, she suffered a prolonged febrile SE and shock attributed to bacterial sepsis. Cerebral edema was documented on a CT scan. The child remained in a coma from which she finally emerged with a severe encephalopathy and minimal consciousness. The seizures stopped. The doctors felt guilty and the child returned to her parents, where she became a kind of "sleeping princess," well cared for by her family. She died at the age of 30, whereas her doctors had predicted a much shorter survival [14].

Discussion

Lia is the main character of a non-fiction book with a strange title, *The Spirit Catches You and You Fall Down*, and an explanatory subtitle, *A Hmong Child, Her American Doctors and the Collision of Two Cultures*, first published in 1997. The author, Anne Fadiman, an experienced American journalist, met Lia in 1988 and spent 9 years studying all of the medical files, the history of her family and of the Hmong people, their customs, the war in Laos, their migration, but also that of her devoted but distraught Californian caregivers.

For the precision medicine supporter, the question arises as to whether the diagnosis of Lennox–Gastaut syndrome, made in the 1980s, would now not be that of Dravet syndrome (DS). The dramatic outcome of the episode, at the age of 4.5 years, attributed to sequelae of septic shock, could well be explained by acute encephalopathy with cerebral edema, a rare complication of DS first reported in 2010 [15]. Its etiology, initially attributed to longstanding SE, is still unsolved. Death or a minimally conscious state with cessation of seizures is unfortunately a frequent outcome, as shown in a cohort of 35 cases from China [16].

Fadiman's book was highly praised by critics, she won awards and became a classic best-seller of narrative and intercultural medicine assigned to students in many faculties. Although it may seem obsolete and set in a small remote town of California, Lia's story is still relevant today because it teaches us about cultural clashes we all experience here and now; and I admit that I have sometimes felt the same incomprehension, distress, and frustration as described by Lia's doctors.

The importance of patient and family narratives, in the context of disability, is also pointed out in a short chapter of *Ethics in Child Health*, a very useful book focusing on practical cases posing serious ethical problems [17]. We often fear we are wasting our time when listening to parents, trying to identify the goals — realistic or not — they have for their disabled child and their life values; but we actually waste a lot more time and energy when there is disagreement on management, when each party sticks to its position and caregivers become exhausted.

Case 5

J., a 9.5-year-old boy, was referred to my outpatient clinic in 2010 by a child psychiatrist for an opinion on behavioral problems and a diagnosis of "Asperger syndrome." He was an "easy baby" with normal early developmental milestones. He had uneventful surgery for an interauricular communication in infancy. Behavioral problems appeared between the age of 2.5 and 4.5 years, with tantrums, provocations, and intolerance to changes. He wanted to command, negotiate, and control everything and made other children cry. He was able to learn at school but had some difficulties in understanding a text and concentrating. Homework was "hell" for the parents, but "when motivated, all of a sudden it was OK". His total IQ was 100, with a verbal IQ of 90.

Deeper analysis revealed an overly rich imagination and strong anxiety over little things. For instance, when he saw a white shade during a walk in a forest, he immediately thought of a mummy and spoke about mummies all day. He often had strange and frightening

[1] http://mamanmathieuetthomas.monsite-orange.fr

ideas and made up new words. He showed either too little or too much emotion and had difficulties in regulating interpersonal distance. He possibly had illusions — "the lamp looks at me" — and hallucinations — "voices tell me..."

On examination, J. was a tense boy "oozing anguish." He had facial tics and often interrupted the history-taking. Eye contact was adequate. He had hyperopia, orthodontic problems, mild background hypotonia, and motor immaturity.

J. is currently succinctly described as a fragile, anxious, rather talkative, but mistrustful young man. He attends a music school with support after having obtained a secondary school certificate.

Discussion

J.'s story draws a peculiar profile, combining anxiety with poorly regulated emotions, social behavior, thoughts, and executive functions. Rather than Asperger syndrome, characterized by social withdrawal and restricted behaviors, his story better corresponds to what child psychiatrists from the psychoanalytical school named "developmental psychotic disharmony": The latter fell into disfavor and first merged with pervasive developmental disorders, not otherwise specified (PDD-NOS, according to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)–4, 1994) and finally ended up in the autistic spectrum disorder (ASD, according to DSM-5, 2013). In order to better define these "atypical" children, dissatisfied American and Dutch psychiatrists came up with the label "multiple complex developmental disorder (MCDD)" in the 1980s [18,19]: They established criteria distinguishing this entity from ASD, which were examined and discussed again in more recent papers [20,21].

Beyond classification issues, J.'s case raises the question of the boundaries between autism and psychoses, in particular schizophrenia. These are clearly clinically distinct but historically closely linked entities. The word "autism" was indeed first introduced in 1911, by the Swiss psychiatrist Eugen Bleuler, to characterize the social withdrawal of adult schizophrenic patients; then, Leo Kanner in the 1940s used it to describe the behavior of children he thought might have an early form of schizophrenia. Subsequently, recognition of the fact that autism was a disorder of brain development separated it from the field of psychosis. ASD now represents a wide continuum that can be associated with numerous comorbidities, especially intellectual disability, as listed in the DSM-5 (2013) and *International Classification of Diseases* (ICD)–11 (2019). However, recent data from epidemiology, neurosciences, and genetics have again brought autism and schizophrenia closer together: Approximately 12% of adults with ASD have a "schizophrenia spectrum disorder." Neuropsychological, brain imaging, and genetic studies have shown many common but also discordant features between both entities, which is not really a surprise [22].

J.'s story raises the following fundamental questions: Could his behavioral phenotype currently embedded in ASD represent a bridge between autism and psychosis? Could children like him be more prone to psychotic decompensation in adolescence and adulthood? Has the definition of ASD become so broad and "elastic" that the application of precision tools inevitably reaches a dead end, just as a magnifying glass put on a blurred image cannot make it any sharper? In my opinion, J. remains in a no man's land in terms of concept, diagnosis, and prognosis.

The list of core symptoms of ASD found in the DSM-5 is of course useful in practice, e.g., to give a diagnostic code that makes it possible to get support services, establish statistics, and send a bill. But we have to admit that it is difficult to imagine what is really covered by words such as "poorly integrated verbal and non-verbal communication" and to teach it to students. For this, there is nothing better than a personal testimony such as that of Temple Grandin, a famous talented woman with autism, who confided in Oliver Sacks on her uneasiness when it comes to understanding human relationships: "I feel like an anthropologist on Mars." And illustrating her lack of access to symbolism "everything was literal to me" with a little story: As a teenager in church, she heard the minister commenting on a verse from St. John 10:9 — "Before each of you there is a door opening into Heaven. Open it and be saved". She then explained how she had to find this door back home and felt so relieved when after a long search she found "a little wooden door that opened onto the roof . . . the door to my Heaven" [23].

One understands even better when watching a video of one of her conferences on the mind of gifted people with autism, and seeing her outfit and how she speaks, starts, and ends her talk ("The world needs all kinds of minds"; TED2010[2]).

Conclusions

With this sinuous itinerary, I hope to have demonstrated that in child neurology an approach by precision medicine does not go without a narrative approach and vice versa. One helps the other but can also take precedence over the other according to circumstances and necessity. These two facets of contemporary medicine are well summarized in this more than a 100-year-old classic question, first formulated by William Osler (1849–1919), that doctors always have to keep in mind: "What disease has the patient and what patient (and family, for the pediatrician) has the disease."

Families of children with neurological disorders clearly demand both: On the one hand rapid and expert diagnosis and effective action on the disease, and on the other hand attentive and compassionate listening to their problems and questions. This is not without generating constant time pressure for the doctor: Other patients are waiting and teaching hospitals have productivity requirements that do not take these needs into account.

Apart from time and costs, precision and narrative medicine approaches have other challenges and limits. For the former, major challenges are data analysis and interpretation, accessibility, ethical aspects [24], and the specter of an algorithm-driven, dehumanized, and socially controlling "push-button" medicine; for the latter, language and sociocultural barriers and emotional exhaustion of the caregivers are a concern, as well as the risk of "artistic vagueness" replacing accurate diagnosis and treatment.

Precision medicine is more familiar to physicians because it relates to pathophysiology, diagnosis, prevention, treatment, and classification of diseases; but narrative skills help not only to better understand and thus manage patients and illnesses, but also to gain experience, remember and teach, and last but not least, to take care of oneself and our teams at times of tension and doubts.

Finally, stepping aside, let us paraphrase Molière when the Bourgeois Gentleman speaks of prose: "We have been practicing precision and narrative medicine for years without anyone knowing anything about it. . .". This to say that one often uses new and trendy words, when actually the tools mainly have changed, and not so much the substance — the patients and the diseases — and one should not be fooled.

Box 1: Narrative medicine: learn more !

1. Principles and methods

Narrative medicine (NM) aims at filling the gap between physicians who know about diseases and patients who live them: The patient's story is central and considered a piece of literature that can be analyzed and understood with tools from literary studies. In practice, the NM approach starts by allowing patients to tell their story in their own words, listening to their

[2] https://www.ted.com/talks/temple_grandin_the_world_needs_all_kinds_of_minds

experience of illness and suffering, and exploring their life context, fears, expectations, and beliefs about disease causality. It then engages to understand the meaning of what has been said and not said, to reflect on the patient–physician interaction and on the physician's own experience and feelings. To deepen the narrative competence of healthcare professionals, NM proposes specific educational programs, literary and writing workshops, and discussion groups [25–27].

The NM movement has raised criticisms regarding both conceptual and methodological issues, but we should retain its teaching of taking genuine interest in the patients stories, an "invitation to be emotionally moved while at the same time retaining the distance that fiction includes" [28].

2. Limitations with pediatric patients

Especially in the developmentally and neurologically impaired, the NM approach appears difficult or impossible, since the ability to tell a story depends not only on age and behavior but also on communication, language, and cognitive levels. The parents, as the main spokespersons, will then bring their own emotions, interpretations, and life experience, which may lead to misunderstandings. One should thus not give up on obtaining the child's productions, since only a short metaphor or a few words expressed orally, in writing, or signs and drawings can provide key information.

Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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