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ESSAY

Everyone Is a Tomato: Metagnostic Narratives of Genetic Revelation

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ABSTRACT

This essay explores the narrative characteristics of genetic revelations as instances of "metagnosis." Contrasting the scientific narrative of increasing knowledge with a series of different stories—including fictional tales—demonstrates the complexity of receiving information that changes one's conception of self, whatever the nature of the revelation. Such narrative awareness can help to communalize such experiences, reducing feelings of isolation and bewilderment.

What is the narrative structure of genetic science? In biomedicine, we seek to better understand the structure and functioning of the human body. Genetic research investigates variants associated with cystic fibrosis, with thalassemia, with various cancers—because understanding genetic factors is interwoven with understanding disease mechanisms, and such expanding knowledge enables us to better prevent, identify, and treat pathology. In cases where our understanding has not yet resulted in effective treatment, we hope that future comprehension may achieve these ends, and so we continue our efforts. While there are many historical and philosophical theories of science, including more historicist perspectives, the premise of any journal devoted to sharing new genomic discoveries is that our wisdom is increasing, and that it may benefit us. Thus one answer to the question concerning the narrative structure of genetic science is that it is a story of advancing knowledge and capacities.

In comparison, what are the narrative structures we *experience* in relation to genetic knowledge? How do they relate to our understanding of the narrative structure of genetic knowledge itself? How might we better understand these experiential narratives—how do we name them, share insights about them, empower ourselves and others to author them in the ways that are most beneficial? What might we learn from the tales we tell in our culture?

Let us attempt to address these narrative questions by taking a brief journey through a series of stories. To start, consider an account of genetic revelation familiar to any genetic counselor or geneticist: Parents who have assumed they are "normal" are surprised to learn that one has a pathogenic genetic variance (a dominant inheritance showing reduced penetrance) and they then have a child who inherits the pathogenic variant and bears the associated condition (with fully penetrant phenotype). This is (literally) a textbook case, with an example appearing in the 2023 *Counseling About Cancer: Strategies for Genetic Counseling*. It begins:

> Jerome, a 35-year-old man, and his wife, Lucia, are pregnant with their first child and met with a genetic counselor to discuss prenatal testing. During the course of taking Jerome's family history, their prenatal genetic counselor learned that Jerome had two paternal uncles in their 60s who both had children who died from some type of childhood eye

> cancer. Jerome did not have details of the family history and had lost touch with his father's side of the family. The prenatal genetic counselor had referred Jerome to cancer genetics. (Schneider, Chittenden, and Shannon 2023, 423)

The narrative continues, describing the lack of further information, barriers to learning more details of the family history, and the couple's mixed feelings about genetic testing. The counselor educates them and they agree to testing, which reveals that Jerome does indeed have an *RB1* pathogenic variant. It is noted that "Jerome had a very flat reaction to the news while Lucia expressed concern for their baby girl." When their baby, Anna, is born, she is found to possess the variant. She is diagnosed with early-stage retinoblastoma at 2 months of age and successfully treated, preserving her vision. The "follow-up" section describes a call with Jerome and Lucia, noting their shock at Anna's diagnosis and Jerome's feelings of culpability concerning the inherited variant. The "discussion" portion highlights the trust built between the genetic counselor and the family as well as the importance of the counselor's role in having the child tested.

This tale, offered in the context of teaching genetic counseling, reflects the narrative of scientific progress, tracing a trajectory of increasing knowledge and its efficacy. It begins with Jerome and Lucia's ignorance of the potential significance of the incidences of eye cancer in Jerome's family; the counselor then guides them toward the revelation of this genetic information, enabling testing and effective treatment of their baby. This arc is framed by the temporal structure, as the story begins with the parents' "presentation" in the scene of prenatal genetic counseling—stepping onto the clinical stage—and concludes with the child's cure and the family stepping off the stage (the "follow-up," by definition, occurs after the conclusion of the primary plot). The narrator is omniscient, unidentified, and the story is narrated in the third person. The clinical details shift into the passive voice—for example, "Anna was tested at birth and found to have the *RB1* pathogenic variant. She was subsequently seen by the ophthalmology team at 2 months and was found to have an early-stage unilateral retinoblastoma" (Schneider, Chittenden, and Shannon 2023, 424). In contrast to Jerome and Lucia, the counselor and clinicians remain unnamed and uncharacterized, lacking detail and emotion, only their actions described; they are representative agents of genomic and clinical information. The narrative is centered around biomedical knowledge: its primacy, authority, and efficacy.

The couple's feelings—uncertainty, shock, guilt—are included in brief references, as addressing them is part of a genetic counselor's task. These painful sentiments are understood to be a justifiable cost of the information, given its essential benefit to Anna. Yet how might other stories illuminate the narrative effects of changing knowledge so as to better understand its operation? One approach is to consider cases in which information is not medically unwelcome per se yet may remain deeply unsettling, provoking complex emotions. For example, clinical geneticist Gail Graham recounts many experiences involving parents of children with developmental disabilities who have assumed some sort of genetic responsibility, only to learn that the child's condition is in fact the result of a *de novo* variant. If Jerome's feelings of culpability for Anna's cancer were burdensome, one might expect the relief of such guilt to be liberating—yet as Graham describes, that is not necessarily the case, and such a revelation can produce "a new, completely different sense of self" (personal communication, May 31, 2021). Might the removal of responsibility also feel like an attenuation of connection? How is it possible to assimilate new knowledge that re-writes a long-standing narrative of one's identity? If it remains challenging, does that help us to understand the *narrative* effects of unexpected information, apart from its direct clinical import?

In contemplating these questions, let us consider another story of new knowledge. Renae[1] begins her account by explaining that she has been told throughout her life that she has achondroplasia, the most common genetic form of dwarfism associated with an *FGFR3* variant. A few years ago, on the advice of her rheumatologist, she consulted with a geneticist concerning a potential autoimmune disease. She describes the encounter:

> I actually have a tattoo on my arm that says *FGFR3*. And [the geneticist] looked at me and said, *you don't have that*. And I said, *what*? She replied, *you don't have that*. I asked, *how do you know*? And she said, *I can just tell by looking at you that you don't have that*. I'm like, *okay, well, what do I have*? And she said, *I don't know, but we'll find out, we'll try to find out*.

Renae undergoes testing, and the geneticist calls her with the results—an *FBN1* variant—"extremely excited that she had found what the mutation was, and basically said that there wasn't a lot of research on it."

This portion of the story echoes the narrative of scientific progress, insofar as the geneticist suggests testing, resulting in a more accurate understanding of Renae's condition. The geneticist's candid remark about the relative lack of research concerning the variant differs from the textbook case in which scientific knowledge is directly tied to crucial clinical efficacy (treating Anna's cancer while saving her vision), but while the information it brings is partial, it is indeed helpful; Renae's mother and aunt also have dwarfism, and the new diagnosis of acromicric dysplasia (which they share) helps to explain her mother's formerly mysterious cardiac issues, and Renae herself now consults her mother's cardiologist annually. As she describes, "we've been medical mysteries our whole lives. Anytime we're sick, anytime anything happens, there's never an answer"—and so the knowledge is welcome to the extent that it offers some demystifying clinical insights.

However, this arc of scientific progress is just one element of Renae's narrative, which is told and structured quite differently from a case report. For example, while the account of Jerome and his family included selected brief references to the subjects' feelings, they were an adjuvant to the primary imperative scientific story of expanding knowledge and its clinical utility. In contrast, here the geneticist's perspective does not frame the narrative; instead, it is told from the perspective of the main character, Renae herself. Her individuality emerges immediately, as she explains that the clinical import of the diagnosis is but one aspect of her experience, and she speaks in compelling

detail about her thoughts, feelings, and experiences. Hearing it in her own words, the listener is very aware of the relational context. Also in contrast to the case study in the textbook, the agent of the genetic information's arrival is a specific person who speaks, who also has feelings—the geneticist who, in Renae's view, was excited to correctly identify the variant. In addition to describing this interaction with the geneticist, Renae highlights connections with family members, friends, and colleagues, and discusses ways in which her understanding of self is forged in this social milieu.

Reflecting the relationality of any storytelling act, for my part, as her interviewer, I assumed or possibly projected an expectation that Renae had "identified" with the previous diagnosis, based on her visible *FGFR3* tattoo. Literally inscribing the "mutation" location on one's skin seemed to be an act of reclamation, perhaps a response to the ways our diagnoses are figuratively read from and then written back onto us by medical science. But she describes it as a "whim": "I don't feel tied to it really in any way, which I should, because it's on my body, but I don't"—adding that she is considering "just getting a line through it and putting *FBN1* underneath it. I think it is kind of an interesting story, and it kind of adds to it." Her ambivalence about the tattoo may reflect the ways in which the experience of the revised diagnosis remains challenging to frame and describe, so it becomes "interesting." Indeed, in describing the effects of the genetic revelation beyond its clinical import, Renae struggles to characterize it:

> It's been kind of odd, I guess ... I've never felt like it's my identity. But I feel like for the longest time, I don't know, you just get put in a box. When you don't fit societal norms or you're a little different or there's something about you—you don't get put in a typical box. And I guess I kind of put myself there in a way. And I don't want to say it was my identity, but it's—I don't know how to describe it—it's been very odd, it was very odd getting that, like having somebody after, what, 25 years, to be like, no, actually, that's not what you have. And you look at my medical chart, and that's what it says is one of my conditions.

How can we depict and better understand what is so *interesting* and *odd* about this experience? Renae's description of her tattoo as "an interesting story" offers a clue—that what is unusual and curious is the *narrative* experience of learning new information that may suddenly shift one's position vis-à-vis clinical and social categories. Indeed, when I learned of my own longstanding undetected visual field "defect," I, too, found the diagnosis to be helpful in some ways; yet the narrative rupture of learning something "new" about myself that had in fact been present all along remained both odd and interesting.

I have sought to better understand why that is the case, and so to begin with, I propose that we can benefit from naming this type of experience—"diagnosing" it, if you will. Following in the tradition of medical neologisms, I have coined a new term: *metagnosis*. One sense of the Greek prefix *meta* is changed, and *gnosis* is knowledge—hence *changed knowledge*. For in addition to bringing new knowledge, the revelation of a longstanding undetected condition often effects a change in the very terms of knowledge, as one's understanding of such categories as normalcy, illness, disease, impairment, and disability may evolve after the experience of shifting so precipitously from one box to the next, absent a new onset disease or injury. Metagnosis describes the diagnosis of a condition that has remained undetected, as was the case with my visual field defect, and/or cases where the diagnostic boundaries have shifted, as often occurs with conditions such as ADHD and autism spectrum disorder. It also describes instances wherein new genetic information changes one's knowledge, whether it pertains to health, as in the cases discussed here, and/or to genealogy (see Spencer 2021, 308–316).

In *Metagnosis: Revelatory Narratives of Health and Identity* (Spencer 2021) I investigate some of the narrative qualities of this type of experience. To begin with, how does it compare with the standard structure of a medical case? Scholar Kathryn Montgomery Hunter has compared the classic diagnostic plot to a Sherlock Holmes mystery:

> The literary genre that has most resembled the case history has been the detective story. The archetypes of the genre, the Sherlock Holmes adventures, were written by a physician. The detective story is not a narrative of illness, but like the physician, the detective seeks to identify the nature of apparently random evil in the world in order to eliminate it ... [The Sherlock Holmes stories] resemble the case presentation, narratives of investigation and interpretation. The narrator in each genre has the task of telling us both "who done it" and how the puzzle was solved. Holmes's ratiocination bears a strong resemblance to clinical reasoning. (Hunter 1991, 169)

We find this clinician-detective model in fictional figures such as Dr. House. Physician-writer Lisa Sanders, author of *The New York Times* Diagnosis column and consultant to the House, M.D. television series, compares the physician's investigation of "modern medical mysteries" to detective work: "Just as Sherlock Holmes ... delights in explaining the crime to victims and colleagues, doctors take pleasure in recounting the completed story of their complex diagnoses, stories where every strange symptom and unexpected finding, every mystifying twist and nearly overlooked clue, finally fit together just right and the diagnosis is revealed" (2009, 13). Similarly, bioethicist Tod Chambers likens the medical case report to a murder mystery, prompted by "a breach in the pattern of everyday life"—"a disturbance in the body" presenting a crime to be solved (2001, 41).

The detective story aptly describes a clinical case report, in which there is typically a diagnostic enigma to be unraveled, and it does characterize some aspects of metagnostic experiences, as in Renae's description of her mother, aunt, and herself as "medical mysteries," with the geneticist playing the role of the eager investigator. But if a Sherlock Holmes tale is always precipitated by a "crime," in many metagnostic revelations its detection and investigation occurs long after the fact, sometimes arising out of

a complete lack of awareness of the condition, as was the case for Jerome and Lucia in regard to his possession of the *RB1* variant, and sometimes seemingly precipitated by accident. Renae was sent to the geneticist to consult on potential autoimmune disease; it was when the geneticist saw *FGFR3* tattooed on her arm (a clue written on her body) that she went on the hunt for the solution to the genetic riddle also pertaining to dwarfism. And in my case, the visual field defect was detected during a standard workup for an unrelated ophthalmic condition; it was not prompted by evidence of any functional deficits. The "breach in the pattern of everyday life," as Chambers puts it, was not "a disturbance in the body," as I had successfully adapted to the "disturbance" long ago (likely a perinatal stroke, so my vision was always my normal, and I function very well). Instead, the breach in the pattern of everyday life was the condition's detection, which was extremely unsettling. The standard medical detective story's diagnostic endpoint was in fact the beginning of a complex process of adapting to this new awareness, renegotiating my own position relative to such categories as normal and impaired.

Indeed, if the mystery story characterizes the process of diagnosing disease, "illness narratives" often have a different structure and scope, reflecting the complexities of lived experience. They are also typically narrated by the "subjects" themselves rather than being told from the omniscient perspective of the clinician-detective. Yet even within the context of illness narratives, metagnostic experiences confound many common patterns of the genre. For example, one way of describing illness narratives arises from sociologist Arthur Frank's typologies: the *restitution narrative* (I'm as good as new after illness); *quest narrative* (illness understood as a journey); and *chaos narrative* (the untellable story) (1997). As he explains, most illness narratives combine several of these elements, and they prove to be quite helpful, illuminating, for example, cases wherein a prescriptive restitution narrative prevents or silences expression of suffering. However, a metagnostic realization does not "fit" any of these story types, for one is not responding to a new disease, but instead to the *awareness* of it (see Spencer 2021, 74). Renae always had an *FBN1* variant, just as I always had a visual field defect. How to tell a story of something you never experienced? How to accommodate a story that abruptly replaces another story? How to account for a condition when your sudden awareness of it is perhaps its most significant quality? Renae's description of the ways "you just get put in a box" pertains to identity, but can also be understood in narrative terms, as we are inscribed within certain stories. Yet metagnosis often does not fit the boxes of the tales typically told of health and illness.

Such narrative challenges are noteworthy, as being able to account for what happens to us—to tell some sort of explicable story and have it be understood—is crucially important. As Kathy Weingarten explains in regard to her daughter's experience with a rare medical condition that does not translate into familiar terms: "Without language, experience dissolves. Without language, experience cannot be shared and community cannot be formed" (2000, 114; see Spencer 2021, 106–115). The importance of communicability returns us to the relational context of the stories of genetic revelation: between Jerome, Lucia, and the genetic counselor, for example, or between Renae, her mother, friends, colleagues, doctors, geneticist, as well as myself, as someone asking questions and receiving her account. We can better recognize the particular metagnostic qualities of these stories by giving them language—naming them—and, reflecting the relationality of stories, by connecting them with other metagnostic experiences, which prove to be far more common than one might expect.

For example, if Renae's story were a classic case report following the structure of a textbook case such as that of Jerome, Lucia, and Anna, it would likely end with the *FBN1* detection. The geneticist would be figured as the detective, assembling clues in order to solve the "crime." But again, the test result was just one plot point, and the story's complexity belies such reduction. Indeed, as our interview was seemingly drawing to a close, Renae asked me about my research and who else I was interviewing, and I explained that we are speaking with people who have had metagnostic experiences of many types, including revelations of longstanding conditions such as ADHD. She animatedly responded that she, too, had received an ADHD diagnosis 2 years prior, at age 28:

> That, honestly, has been more life-changing for me than the diagnosis of having acromicric dysplasia. Getting the diagnosis later, I'm like, *wow*—my life could have been—my experience in school could have been different, work could have been different. So many things. So many aspects now make sense. I'm like, *oh!* Or things that I thought about myself, like, *oh, you're lazy and you're just not motivated*—no, that's not the case. Getting that diagnosis was way more life-changing [laughs].

Renae's response reflects the experience of many adults navigating an ADHD diagnosis, reflected in such titles as *You Mean I'm Not Lazy, Stupid Or Crazy?!: The Classic Self-Help Book for Adults with Attention Deficit Disorder* (Kelly and Ramundo 1993). Often the diagnosis offers clarity and the relief of lifelong shame and guilt. For example, Robert Jergen's first visit to an ADHD support group was "like the heavens had opened up and the Holy Choir was singing … I can't describe the weight that lifted off of me. Years of failure. Years of isolation. Years of pain, anger, depression, anxiety, hatred, and frustration were suddenly explained" (Jergen 2005, 92; see Spencer 2021, 278–287). This first stage is often followed by an awareness that the condition's "symptoms" are interwoven with one's identity in positive ways. For example, Wolkenberg describes his ADHD as associated with his sense of the absurd as well as his funny and compelling qualities, and his accumulation of an "eclectic but interesting body of knowledge with a better view of the big picture" (1987, 82). Indeed, metagnosis is often characterized by such varied and complex responses.

If we intentionally draw connections between genetic revelations and other types of metagnostic experiences, then perhaps that will give us tools to help reduce the narrative challenges and associated bewilderment and isolation that many individuals and families experience when facing genetic news that comes seemingly out of nowhere. We tend to remain focused on the

context of a particular "condition," but metagnostic surprises arrive throughout life under many different circumstances, and they often share narrative characteristics. Moreover, they will keep occurring and at times reversing as our knowledge continues to evolve. For example, many adults were diagnosed with "Asperger syndrome" when it entered the DSM—and then, 13 years later, found that the condition was no longer recognized, partially absorbed into autism spectrum disorder (see Spencer 2021, 261–272). Or in my case, I learned that I do not perceive the right half of my field of view, only to discover later that I do possess unconscious vision and motion detection in that "blind" hemifield. As with parents learning that their child's condition was not in fact inherited from them but instead the result of a *de novo* variant, finding that one does *not* have a condition in the way one has understood can be just as unsettling as receiving a "new" diagnosis.

While plot twists like these might seem anomalous, metagnostic revelations are not aberrations. They are the nature of the human condition. One way of contextualizing and communalizing these experiences is to look to the fount of stories that we have told throughout human history, where such narrative surprises play a key role. In Sophocles' *Oedipus Rex*, for example, we find a classic exemplar of what Aristotle called *anagnorisis*, or recognition—a coming to knowledge about oneself. In this case, Oedipus learns that he has fulfilled the fateful prophecy of killing his father and having sex with his mother, producing a drastic reversal of fortune. Another example of anagnorisis occurs in Homer's Odyssey when Odysseus finally returns home after 20 years, seemingly a stranger, and then his distinctive scar is recognized, revealing his identity. As literary scholar Terence Cave points out, what is deeply unsettling about any such experience of recognition is the awareness that "the commonly accepted coordinates of knowledge have gone awry" (1988, 2).

Such revelations may upend the individual's story of self. When the knowledge is unwelcome, as in Oedipus' fate or Jerome's *RB1* pathogenic variant, the upset can be understood in that context, as it is distressing to learn bad news. But again, the effect often persists even when the information might seem to be welcome. Turning to contemporary storytelling, we find an example in "No Strings Attached," a 2003 episode of the television series ER, set in the fictional Cook County General Hospital Emergency Room in Chicago. Here a new character, Stanley, presents to the ER, requesting a B-12 shot to treat symptoms of pernicious anemia; he is an expert on his condition, and President of the Victims of Pernicious Anemia organization. However, his test results are not consistent with the diagnosis. "You don't have the disease," Dr. Pratt tells him. "You never did." Assuming that Stanley will be pleased to hear the "good" news, Pratt instead finds him lingering in the waiting room after discharge, looking morose and lost. "Thought you'd be out painting the town by now," he remarks, to which Stanley replies, "Huh, all my friends are too tired to go out ... they all have pernicious anemia. Everything in my life was built around it. Support groups, therapy, committees ... so, what do I do now?" From a strictly medical perspective, the knowledge is good—hence the doctor's expectations—but understood as an experience of anagnorisis, such a revelation brings its own distressing challenges to the individual's narrative of self and sense of agency. What does he do now? Moreover, the existential implications extend well beyond any particular revelation. As Cave describes, "anagnorisis is distinctively awkward because it raises the question of knowledge and more particularly of a dubious or disturbing knowledge" (1988, 7). Knowledge has lost its foundation; it may always change: *meta-gnosis*.

Contemporary speculative fiction offers many such tales in which a character learns something new about themselves, to the extent that (again, speaking of naming things) this plot twist has a name, "Tomato in the Mirror," as when a character looks in the mirror and realizes they are actually a tomato—or more likely a robot, clone, undead, and so forth (TV Tropes 2024b). It is a variant of the "Tomato Surprise" plot twist, named by the editors of *Asimov's Science Fiction* magazine to describe times when "the evil, horrid aliens that turn out in the last paragraph to be humans from earth [or] the converse, in which what the reader assumes to be human characters are revealed in the last paragraph to be giant lobsters or worse" (Scithers, Schweitzer, and Ford 1981, 112). Philip K. Dick's oeuvre is rife with tomato-in-the-mirror revelations, as in his short story "The Electric Ant" (1969) featuring a character who believes himself to be human, only to injure his arm and find circuitry beneath his flesh. Dick's (1968) novel *Do Androids Dream of Electric Sheep?* was adapted as the 1982 modern classic film *Blade Runner* (Ridley Scott) in which a character, Rachael (Sean Young) learns that she is not human, as she had thought, but in fact a "replicant" robot. Notably, the Director's Cut (Scott 1992) raises the prospect that the replicant-hunter protagonist Deckard (Harrison Ford) may also be a replicant, though he understands himself to be human, prompting the audience to consider the unsettling possibility that one could learn something that produces *a new, completely different sense of self* (to use Graham's description of the effects of some genetic revelations) and that our stories may always change, particularly in an era of rapidly evolving knowledge (see Spencer 2021, 175–187). The successive versions of *Blade Runner* (prototype, theatrical release, director's cut, final cut, etc.) multiply the unsettling effects of anagnorisis—that the tale could transform, and transform yet again. As Cave describes, Odysseus' scar confirms his identity, but it is also "a mark of treacherously concealed narrative waiting to break the surface and create a scandal; it is a sign that the story, like the wound, may always be reopened" (1988, 24).

While metagnosis is a common theme in the speculative fiction genre, the Marvel "X-Verse" offers many metagnostic tales that are specifically pertinent to genetics, as this is a world of superhero "mutants." Characters are often surprised to suddenly learn of their mutant status and associated superpowers, and must grapple with a radically altered sense of identity and the implications of diverging from societal norms, not fitting into conventional boxes. For example, in one of several versions of his origin story, one of the key X-Men characters, Logan—protagonist of his own series of dedicated comics and films—learns of his mutancy quite suddenly and shockingly at the beginning of *X-Men Origins: Wolverine* (Gavin Hood 2009). As a boy named James Howlett (Troye Sivan), his loving father is murdered by a neighbor, whereupon claws spring from James' knuckles and he murders the attacker, only to learn that he has killed his own genetic father (see also: Oedipus). His mother, horrified, cries, "*What are you?*" He runs away, and over many years (and many versions of the story) his identity continues to shift. Known

alternately as Logan and Wolverine, his search for belonging continues, with much angst and struggle, and the metagnostic revelations and reversals continue to accelerate. Indeed, in one plot line it is divulged that he is *not* a mutant but in fact a "Lupine," or wolf-descended human; however, that turns out later to have been a deception. Logan's suffering and his epic search for home—a journey worthy of Odysseus—speaks to the fear of what might happen upon learning something that unmoors us from what we think we know about ourselves. Might we face such a tragic fate?

What is the relevance, if any, of these fictional tales to real-life stories of genetic revelations? For one, we have created these stories as a reflection and means of exploring meaning in our "real" world. Reciprocally, the public's views of genetics are informed by exposure to media of all types, including fictional genres (see Roberts et al. 2019). Moreover, one of the central themes of the X-Verse is the mutants' efforts to form family and community, and we, too, seek to communalize the challenges we face when we find ourselves apparently varying from customary experience. If metagnosis is often bewildering and isolating, we can look to others' experiences, and to the stories we tell as a culture, to emphasize that they are far more common than we may have thought. Indeed, in lieu of the "Tomato in the Mirror" trope, we might find another that is more apt: "Everyone is a Tomato," which involves "creating a fictional subcategory that can be applied to any character, treating it as some sort of rarity or shocking twist, and then applying it to most or all of the cast" (TV Tropes 2024a). If metagnosis evokes feelings of isolation and disempowerment, then there is some consolation in the fact that all of us will face revelations of one type or another that will change our knowledge of ourselves. If not now, then in the near future, as we accelerate into an era of rapid evolution of our understanding.

Which returns us to the story of expanding scientific knowledge where we began our narrative journey. As this series of unfolding stories demonstrates—from a textbook case, to a real-life first-person account, and onward to fictional tales—the arc of progress is but one story-structure among many. Our lived experience is narratively complex, and our stories unfold to other stories, and they speak to one another and respond to one another. If we understand surprising genetic diagnoses as metagnostic experiences, then we can connect them to similar revelations, from other metagnostic medical diagnoses to fictional and speculative domains which we create in order to reflect upon and better understand our own world. And we can ask ourselves: What sort of narrative capacities might we liberate in order to imagine our own futures?

The Metagnosis Project aims to explore a range of metagnostic stories and to reach a broad audience, empowering and supporting individuals and clinicians in navigating this experience. If you have had a metagnostic experience, have suggestions of interesting examples, or would like to learn more about the project, please consider sharing on the form at www.metagnosis.org.

Data Availability Statement

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

Endnotes

[1] This individual's name has been changed in order to protect their privacy.

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