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The Body Discourse and Dystopian Identity Narratives of Women with Turner Syndrome

Abstract

The aim of the article is to compare and contrast dystopian discourse with the first-person life narratives told by females with a rare genetic disorder, Turner syndrome (TS). Employing the methodology of discourse analysis, I trace the themes related to the most challenging areas of the lives of women with TS, and find certain tendencies in the way they position themselves and others in the contemporary discourse of medical treatment, femininity and social relationships. I analyze stories whose characters are developed on the basis of experiences that their tellers lived through. I argue that the discourse of Turner syndrome and the dystopian discourse are analogous on the grounds of the rarity of the syndrome and its two main symptoms — short stature and gonadal dysgenesis.

discourse analysis, dystopia, identity, narrative, positioning, Turner syndrome

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1. Introduction

Literary genres require specific types of characters to be created, i.e., they should bear a number of traits that are assumed to be typical of that particular genre. However, while dystopian protagonists are typically found in dystopian novels, some of their characteristic features may also be observed in characters portrayed in other genres. A typical dystopian character, developed in such novels as *Ninety Eighty-Four* by George Orwell, *Brave New World* by Aldous Huxley, *Fahrenheit 451* by Ray Bradbury, or *The Hunger Games* by Suzanne Collins, encompasses a minimum of four main qualities pertaining to the activities and behavior of the character, their relationships with other characters and their position in the story world. The four predications, *viz.* (i) feeling trapped and struggling to escape, (ii) believing something is wrong with the society, (iii) questioning the existing social and/or political order, (iv) helping the audience recognize the negative aspects of the dystopian world through his/her perspective, form a schema that enables the construction and recognition of the dystopian protagonist, which, in turn, helps organize the plot and express concerns about issues of humanity and society (ReadWriteThink 2006). The archetype of the dystopian protagonist involves acts of questioning, rebellion and warnings about the current condition of the state or of those in power; and this makes the novel action-packed and intricate.

In this article, I aim to compare and contrast the dystopian discourse with the first-person life narratives told by females with a rare genetic disorder, Turner syndrome (TS). I will analyze fragments of stories whose characters are constructed and developed on the basis of experiences that their tellers lived through. I argue that the dystopian discourse and women with Turner syndrome can be regarded as analogous on the grounds of the rarity of the syndrome and its two main symptoms — short stature and gonadal dysgenesis

Before the analysis is conducted, I will first discuss the main symptoms of Turner syndrome in order to delineate the similarities and differences that might be conceived between TS subjects and dystopian discourse. Then, I will devote some space to the characteristics of dystopian narratives vis-à-vis stories delivered by TS subjects. Finally, employing the methodology of discourse analysis, I will trace the themes related to the most challenging areas of the lives of women with TS, and find certain tendencies in the way TS subjects position

themselves and others in the contemporary discourse of medical treatment, femininity and social relationships. This should ultimately show how the identity of a woman with TS compares and contrasts with that of the dystopian protagonist.

2. Dystopias of Turner syndrome

Turner syndrome is characterized by the lack of an X chromosome and dysgenesis of the ovaries; its carriers are phenotypically female but lack naturally developing secondary female sexual characteristics. In addition, women with TS tend to be short in stature and may demonstrate a webbed neck, puffiness of the hands and feet, and skeletal abnormalities (Hutaff-Lee et al. 2019; Rieser, Davenport 2019; Zadrożna 2013). "In genetic terms, these patients are neither male nor female because the second, sex-determining chromosome is absent. However, phenotypically, affected individuals develop as females because there is no Y chromosome to direct the fetal gonads to the male configuration" (Zadrożna 2013: 122).

A common form of treatment, which is also considered to befit TS individuals to a socially accepted female beauty representation, is hormone replacement therapy (HRT) enforced on them early in their life and thus without their conscious consent. From the medical perspective, the procedure is considered beneficial since TS women experience a number of unusual bodily characteristics related to sexual development, and HRT compensates for them. As a result, the recipients of the therapy demonstrate improved psychological wellbeing and self-esteem (Hutaff-Lee et al. 2019; Toft, Rehan 2014; Zadrożna 2013).

With a change in perspective, TS can be viewed in terms of two different forms of dystopias. From an etic view, the abnormalities like short stature or lack of breast growth may serve as a source of social discrimination, prejudice and exclusion. TS women are seen as "putty in the hands of fate" (Claeys 2013: 17), and therefore the imposition of HRT supposedly takes them from the dystopia of TS to the "utopia" of the non-impaired. In this regard, HRT is like "the quest for utopia seen in terms of perfectibility" (Claeys, 2013: 17), one that demands a remake of the natural human body, ostensibly and permanently for the better.

From an emic view, however, the symptoms of TS can form the basis for personal identity construction and for the bearer to recognize herself as different, and therefore unique, in terms of bodily appearance and her prospective social roles. Rieser and Davenport (2019: 2) note that "[e]very girl with TS is unique and no generalization will apply to every girl, no matter how accurate it is for the group" despite a common neuropsychological profile reported by other researchers (Hutaff-Lee et al. 2019). Therefore, medical treatment and HRT suppresses what is individual and subsumes the TS carrier into the communal and normative.

The discourse of dystopia encompasses gender identity and sexual identification. One can perceive some analogies with regard to these problems in TS identity narratives. Genetically, TS individuals are neither male nor female because one of the sex chromosomes is missing from their genotype, but they are assigned a female gender at birth, because phenotypically they are female (they have the vagina and uterus); therefore, HRT aims to adjust their appearance to culturally-accepted femininity. However, not all TS women identify as female later in their life. Thus, with sex assignment "human volition has been superseded [...] by an authoritative imposition of control from outside (Claeys 2013: 17).

Sexuality and reproduction are also "dystopian" aspects of Turner syndrome. Due to other methods of reproduction (i.e. cloning or non-organic, robotic origin), the female characters in dystopian narratives frequently suffer from infertility. Sexuality means the freedom

to be sexually active (or not) with the partner of one's choice, while reproduction indicates the ability of each individual to choose when (or if) to conceive a child. Possessing an unattractive body, TS women are severely sexually deprived — they do not choose their partners; rather they are positioned as objects of someone else's choice, not the most desired, though. As for reproduction, even with years of estrogen replacement therapy, it is rare for a woman with TS to naturally conceive a child. While fertility treatments help increase the chances of having a baby in women with functioning ovaries, pregnancy can be risky for patients with TS due to the risk of developing a heart condition or kidney failure. Hence, sexuality and reproductive control are removed from the hands of individual women with TS. Their identity is regulated by the physical body through hormonal therapy, removing personal choice and freedom, and determining their sexuality. HRT, however, unlike the drug from *Brave New World*, does not bring "instant gratification" with childbearing; the guilt and pain remain, and the greatest desire lingers unfulfilled. As a result, TS women "fit snugly into their place in society, genetically decanted" (Kumar 2013: 21).

One last aspect of TS dystopia results from the early commencement of HRT, when the girls are underage and cannot engage legally in such activities, thus violating their right to self-determination and independent decision-making. Similarly to dystopian characters, TS girls "are merely pawns in the hands of others", which goes against the popular supposition that "[m]odern politics [...] is intended to give us deliberative and executive authority or collective control over our conditions of life" (Claeys 2013: 17).

To sum up, in this section, I have outlined two different types of dystopian discourses resultant of two different perspectives on the issue. From the etic view it is the syndrome itself that is dystopian and therefore certain measures imposed on TS females aim to benefit them. From the emic view, dystopia derives from the imposition of HRT administered without the subject's conscious consent, thus evoking the sense of the powerlessness of TS girls in the face of an oppressive society organized into institutions. What is more, the outcomes of HRT are far from satisfactory, which renders HRT, like utopia, impractical and idealistic.

3. Dystopian and biographical narratives

Narrative, as an object of inquiry in the humanities and social sciences, escapes any straightforward and agreed-upon definition. In the structuralist tradition, narrative texts are claimed to share four features, (i) a series of temporally or causally-related events; (ii) a form of a complication or disruption; (iii) goal-directed actions and reactions to deal with this disruption; (iv) an animate protagonist (de Fina, Georgakopoulou 2012: 6).

In identity research, biographical narrative prevails where "[t]he guiding assumption has been that the telling of stories allows the teller to bring coordinates of time, space and personhood into a unitary frame so that the sources «behind» these representations can be made empirically visible for further analytical scrutiny in the form of «identity analysis»" (de Fina, Georgakopoulou 2012: 159). Language processes are used to form the identity of the protagonist; that is, it is through the use of language, people name, construct, contest, and negotiate social identities. Naturally, predication, being a very basic language process, becomes the focus of the analysis. Reisigl and Wodak (2001: 54–55) claim that "through predication, persons, things, events and practices are specified and characterized with respect to quality, quantity, space, time and so on." Predication, at the basic semantic level, codes events, and individual examples of predication, in turn, are sequenced to yield a narrative structure.

Narrative displays how prior experiences are transformed and symbolized in linguistically represented networks of events, processes and states.

Although dystopian narrative shares the core formal properties of narrative genre with life narrative, it also differs in some aspects. In most cases, dystopian narrative is fictional writing that explores social and political structures characterized by poverty, destruction and oppression that developed from "the colossal failures of totalitarian collectivism" (Claeys 2010: 108) of the twentieth century, and its structuring theme, as Terentowicz-Fotyga (2018: 15) argues, "is the relation between the individual self and the oppressive, monolithic state. The plot usually develops when a protagonist awakens to the true nature of social-political reality and starts to rebel."

The construction of space is also claimed to be a defining characteristic of dystopian narrative. As Terentowicz-Fotyga (2018: 16) argues "[t]he lines separating the private from the public, the individual from the communal, the intimate realm belonging to the self from the shared (or transgressed) space controlled by the state, become an important source of narrative dynamics — either because the boundaries exist and are transgressed or because they do not exist and the reader is expected to interpret the lack in negative terms". This has consequences for the dystopian thematization of the tension between private and communal spaces. Frequently, private space is destructed, while different forms of communal living, including surveillance systems, thrive on that. The erosion of the boundary between intimate and shared is further revealed in the tendency of the state to bring the body under control in, for example, monitoring food consumption, procreation, or by imposing specific bodily beauty standards or healthy living practices.

Despite differences, the two narrative subgenres share some elements. First of all, they both present subjective interpretations of social and political systems, take an evaluative stance and "criticize, unmask and investigate not only the imperfections of the present-day society but also of the alternative society" (Fortunati 2013: 28), with the protagonist being the main determinant of perspective for the reader. The narratives focus on the "alienating effects of science and technology" (Aldridge 1978: 18), and go beyond the experience of individual alienation to explore social consequences. Their protagonists are no longer passive followers of orders but individuals who are capable of reflecting on their condition and position, and who actively explore their human potential to change an unsatisfying reality. They can feel trapped in their life but they struggle to escape or battle to achieve a better world. Having failed, and being treated as outcasts by society due to their appearance, behavior, beliefs, or other characteristics that are in conflict with the norms of the world, they attack existing social structures, because they believe that something is wrong with the society in which they live rather than with themselves.

4. Dystopian identity narratives of women with Turner syndrome

The present paper, based on a discourse analysis of narratives published on the webpage of the Turner Syndrome Society of the United States, aims to reveal certain tendencies in the way TS subjects position themselves and others in the contemporary discourse of medical treatment, sexuality, femininity, and social relationships, and compares and contrasts their identity with that of the dystopian literary protagonist.

4.1. The protagonist feels trapped and struggles to escape

The stories represent the subjects' comprehension and expression of their feelings about their condition. The authors see the fault in their genetic design that manifests in their bodily appearance ("short stature, elephant like feet, a lot of weight gain from the growth hormone, looked like I was 12, not 15" — Odom 2018), physical condition ("motor clumsiness, having a lazy eye, I try to keep my body together, vision impairment, hearing loss, hypothyroidism, arthritis hypertension, heart irregularities, breathing issues" — Gabl 2018), and ability to reproduce ("I am still a virgin, I have not had sex and I am in my late twenties, I was infertile and had my ovaries removed" — Whitaker 2018). The physical outcome of their genetic design contrasts with that of a woman or a human being prevalent in the society. A typical individual of female sex has ovaries and a vagina, and later in life develops female secondary sexual characteristics, such as breasts or menstruation. These translate into feminine gender characteristics such as gentleness, empathy, sensitivity, caring, compassion, tolerance, nurturance and deference. As women with TS do not naturally develop such characteristics, the dystopia, the metal horseshoe, resides in the body of the protagonist rather than in society. The regular human karyotype is unreachable for TS women, and hence a form of utopia for them, and HRT represents the battle they lead against the dystopia of their body. The outcome of the battle is in most cases unsatisfactory ("don't treat me like the adult I am, I always felt lonely and wondered what was wrong with me, the metal shoe always lodged in the mind" — Whitaker 2018), which reminds us of the dystopian protagonist who usually fails.

The thematic preoccupation with the body found in the TS narratives is common in dystopian narratives. In both cases, it can be seen as a corollary of the semiotic importance of the tension between private and public spheres. The body is portrayed as the site of conflict between the individual and the social. In the TS narratives, however, it is the individual who wants to bring the corporeal under control rather than protect it, while the social helps them to attain that goal. The TS protagonists struggle with the aspects of themselves that do not fit into society's norms and expectations that are perceived as positive, and TS women often feel out of place and disconnected ("friends do not know about their condition; it's difficult to explain it to boyfriends" — Polashek 2018). The physical trap of the corporeal translates into a social trap that deprives the TS individuals of the benefits that those without TS enjoy.

In contrast to dystopian narratives, the boundary between the private and the social represented in TS narratives does not become erased, but rather mounts and the protagonist aims at its destruction. The physically grounded experiences ("shopping for clothes in children's departments, being offered child's menu" — Canton 2018) lead to misconstruction of social identity and isolation ("I couldn't relate to them; It was an odd feeling, I am so hostile towards other people, have little patience for them" — Whitaker 2018). Therefore, the TS protagonists strive to escape the custody of the body and become ordinary members of society. Unlike dystopian protagonists, TS subjects do not subvert social dystopia but rather resist individual otherness and aim to attain social oneness where the individual is no longer distinct from the collective whole. They struggle to become collective while still maintaining the individual traces that TS instilled in them. It is the genetic design rather than oppressive society that leads to disillusionment and despair.

4.2. The dystopian protagonist believes something is terribly wrong with society

Discussing the beliefs of TS women about their functioning in society is a tricky task because Turner syndrome is related to impairments in social perception that frequently manifest in mental inflexibility (Hong, Scaletta Kent and Kesler 2009); this, in turn, can result in an inability to cope with changing social situations, and affect the ability to acknowledge another person's perspective. Therefore, the views presented by TS women regarding their position in social environments can be argued to be inadequate. Nevertheless, the high frequency with which the issues of stigma, social isolation and loneliness are raised in the stories by TS women entitles any reader to believe that these are neither subjective impressions nor random experiences but recurrent occasions on which TS individuals feel and face these phenomena in the community.

Although most of the subjects say they feel "good" about having TS, concerns become evident when the perspective is diverted, and they have to talk about their being members of society, ("I always have so many bumps in my road, growing up was hard for me socially," — Odom 2018; "you feel like others can not relate to you and why you would resort to pushing others away and distrusting them" — Whitaker 2018). The stories reveal that a socially prevalent view of TS is a deficit model of disability, where individuals are perceived not only as different but also deficient ("but that does not mean that I am not human or having a human life, my friends call me a mermaid," — Canton 2018; "there was no way I could have a healthy life, being bullied for being short and for having a lazy eye" — Carley 2018). Similarly to dystopian society, in which different forms of social interactions are either forbidden or at least discouraged, TS narratives typically portray them as heavily impaired or destructed. The destruction of the body represents the grounds for the destruction of private space, which, in turn, leads to the disintegration of family life or intimate relationships.

The breakdown of the latter is attributed by the TS protagonists to their lack of the desirable, feminine, Barbie-like appearance prevalent in society and overrepresented in the media, where women are tall and slim ("I was put on medicine to help me grow and to go through puberty. I also reached out for help with my depression" — Hartsell 2018). Unlike dystopian protagonists, however, the TS women neither question the hegemonic discourse of feminine beauty nor struggle with the aim of transforming it to adjust to their needs and desires, but instead make attempts to alter their appearance in order to conform to social norms ("it was so hard finding someone, but see how your health has been a constant battle, and how it makes you feel like others can not relate to you, I relate to others through common interests and like-minded hopes, dreams, and desires that are universal" — Whitaker 2018).

The disintegration of social bonds, in stark contrast to the dystopian omnipresence of the communal, is perceived as a consequence of the rarity of the syndrome and the lack of knowledge and education in society. Hence, disclosure becomes a significant issue for many TS women. They state that they find it difficult to disclose their diagnosis to others, and as a result feel that their friends and peers do not have a complete understanding of them or their condition ("they called me mermaid" — Canton 2018). While most of the subjects reveal that they receive emotional support, reassurance and encouragement from their family ("my parents helped anyway they could, consoling me and telling me they would buy me height if they could, My parents did as they were told. They took me home and loved me as much as they could" — Gabl 2018), supportive behaviors are rarely observed in school or work environments ("Growing up was hard for me socially, I was so lonely from struggling to

relate to my classmates I would yell back at the kids, and try to stand up for myself" — Odom 2018). In the majority of the stories, a theme of isolation resultant from the lack of feminine characteristics can be seen, as well as aberrant physical appearance misunderstood by others due to their ignorance about the syndrome.

Apparently, the lack of knowledge about the syndrome and the difficulty in its disclosure acknowledged by the TS women, contradict the dystopian construction of social relations in which characters are deprived of any sense of privacy and individualism and where communalism is promoted instead. For TS women, the private is their dystopia. The private sphere includes a family which is either non-existent or subordinated to the principles of the state in dystopia. In TS narratives, the family is the soil which nurtures the characters and enables their development. Nonetheless, the subjugation of individualism and the rule of the public is observable in the strong desire of TS women to conform to an ideal of femininity, including the maintenance of feminine beauty standards, feminine sexuality and such feminine social roles as wives and mothers. The communal has been internalized and it structures the plot of the TS story from within the protagonist.

4.3. The protagonist questions the existing social and/or political systems

Throughout the stories, the tellers expose the pros and cons of HRT, and disclose their feelings about the attitude of society to them. They often admit that HRT was necessary and even beneficial to their health ("prescribed an estrogen patch and progesterone pill, which seems to work much better for me, I appreciated hearing better" — Polashek 2018), like the road to utopia in dystopian narratives, yet the way it was designed and executed made the TS women feel objectified and outcast ("I am not a freak, I decided to take control of my story, Turner syndrome–means being unique, not superior" — Whitaker 2018). Neither their peers nor other family members went through such procedures, so they could not share their feelings with them, or the medical staff, to relieve their suffering ("the hardest thing has been explaining my diagnosis, people do not understand me, they could not be me even if they wanted to" — Canton 2018).

The feeling of isolation intensified in school years when the TS girls experienced bullying from their peers with whom they could neither relate physically nor emotionally because of their delayed emotional development and maturation ("I want to be real, not a story of someone diagnosed with a rare genetic condition"). Nevertheless, unlike dystopian protagonists, the TS women do not blame others for their rejection and alienation; rather they consider their abnormal genotype reflected in their anomalous appearance to be the main reason of their social exclusion.

The awareness of being different is frequently the basis on which TS women construct their self-image ("People tell me I am interesting and have a good story, but I want to be real, not a story of someone diagnosed with a rare genetic condition" — Whitaker 2018). On the other hand, the feeling of being different can serve as a source for questioning the existing social order. It is not solely the TS subject who self-positions as different: their othering also results from the perception and attitude of the society ("you do not have to be defined by what others say" — Whitaker 2018). The TS protagonists are treated as social outcasts due to their appearance and behavior that conflict with the norms of the dominant, yet dystopian, discourses of beauty and femininity. Hence, the alienating effects do not come so much from science and technology (Aldridge 1978) but from the corporeal.

Nevertheless, HRT can be seen as a source of alienation originating from science. The effort and struggle associated with HRT are beyond the comprehension of other members of the society, who are incapable of sharing the experience with TS women. On the other hand, however, HRT is the resource that unites women with TS with society as a whole, as it helps achieve a desired feminine appearance. This implies that the dystopia of the body can be defeated, by which TS women can become full-grown members of society.

In contrast to protagonists in the dystopian literary and cultural discourse, whose disillusionment and despair arose from events during the first few decades of the twentieth century (Claeys 2010, 2017; Terentowicz-Fotyga 2018), the TS protagonists are disillusioned with HRT, whose beneficial outcomes neither compensate for the harm done to them by peers in school or members of medical institutions, nor for the effort invested in HRT. Therefore they question the social order which forces them to adapt their bodily appearance to the femininity approved of in the dominant discourses. Still, they do not make a direct attack on the existing social order but rather "settle for a passive rejection of social structures and a withdrawal into self" (Aldridge 1978: 16) or into the private sphere.

4.4. The protagonist helps the audience recognize the negative aspects of the dystopian world through his or her perspective

Unlike a dystopian discourse, where audiences recognize the negative aspects of social structures throughout the story, the audience of the life stories is addressed in their codas, where the tellers recurrently exit and return to the story world of their TS condition. The purpose of the stories is for TS individuals to support others by sharing the story of their life ("DO dream big!" — Polashek 2018; "This life isn't always easy, but it's always worth it," — Carley 2018; "I love my crazy, busy life!" — Hartsell 2018) rather than encouraging others to fight an oppressive state. The TS women seem to be aware of their limitations ("Be humble, for you are made of Earth, if I can do one hard thing, I can move on to conquer another hard thing" — Williams 2018), and their stories serve basically to inspire others to openly discuss their condition and all the challenges they have to face ("I am going to help spread awareness and help others, a new role of supporting us to find out how to heal the pain" — Odom 2018), as well as see the possibilities of living the life to the fullest ("I am going to embrace who I am fully" — Odom 2018).

The TS protagonists make the audience aware of "the dystopia" that resides in their self rather than the external space ("discover how to remove the metaphoric horseshoes" — Whitaker 2018). So, in contrast to protagonists in dystopian narratives, they feel obliged to spread the awareness of that internal dystopia, which is completely unknown to others ("I want physicians to know where to go and get information, the lessons growing up with TS taught me" — Odom 2018).

5. Conclusion

The aim of the paper is to analyze the portrayal of women with Turner syndrome that emerges from the stories they deliver, and compare it with that of the literary dystopian protagonist.

Conversely to dystopian literary or cinematographic protagonists, the TS women are shown to often feel trapped in their own bodies rather than in the existing social order. They struggle to escape the genetically deformed body and conform to, rather than oppose, the standards of femininity that dominate in the contemporary world. They acknowledge

that their bodies are the source of ostracism, which implies that they indirectly oppose and subvert the standardized discourses of femininity. They "present egalitarianism as mere illusion: it is a well-organized hierarchy of power that holds the world together by denying individuals their natural freedom" (Mihailescu 1991: 215).

From this perspective, HRT (its value infrequently questioned) is like a relentless pursuit of "impossible" happiness; a "mass-delusion" that offers protection against suffering through a delusional "remoulding of reality" (Booker 1994: 11). The outcomes of HRT rarely fit the TS individual into the socially dominant ideal, so the TS protagonists usually fail in their fight to obtain "utopian mainstream" body characteristics. While the outcomes of the HRT may be satisfying, the therapy itself is often seen as limiting individual liberty and promoting the communal. In this sense, HRT is harmful when aimed at establishing one socially approved ideal of femininity.

TS women also evoke the traits of a literary dystopian protagonist through the ways in which they rebel and acknowledge social iniquity. Not only do their actions demonstrate their refusal to accept the perpetual lack of individualism inherent in society, as well as self-made choices about HRT and privacy, but they also provide the readers with the sense of rebellious action that they crave. They are aware of their desires and look to move within and beyond societal constraints.

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