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THE HORMONE OF GROWTH AND HOPE. THE CASE OF TURNER SYNDROME

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Turner Syndrome (TS) is a condition that affects only girls and women and involves a partial or complete absence of the X chromosome. It is a well recognized medical condition and a multidimensional cultural fact that has appeared in specific historical, social and geographical contexts. TS is characterized by, among others, short stature, and ovarian failure. Girls with TS are put on estrogen replacement therapy and growth hormone treatment, which means a daily injection, starting at around 5 years of age or later and usually continuing until around 15. Without this treatment, girls suffering from it would be on average 20 cms shorter than women unaffected by it. In this text, I intend to look at the biosocial work of the growth hormone. I examine the purpose of it, and describe the work of hope being carried out in reference to hormone treatment. It is a technology, which is adaptable and flexible and from my perspective, hormones are "fluid objects". I present both the daily regimes and the regular biomedical controls taking place regarding GH treatment, describe the private and public histories of growth hormone therapy, and analyse an experience of the materiality of hormones, focusing on a pen injector device.

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Zespół Turnera (TS) jest stanem, który dotyka jedynie dziewczynki i kobiety i obejmuje częściowy lub całkowity brak chromosomu X. Jest to uznana jednostka medyczna oraz równocześnie wielowymiarowy fakt kulturowy, który pojawia się w specyficznym kontekście historycznym, społecznym i geograficznym. TS charakteryzuje się między innymi niskim wzrostem i niewydolnością jajników. Dziewczęta z TS są poddawane estrogenowej terapii zastępczej i leczeniu hormonem wzrostu, co oznacza codzienną iniekcję, począwszy od około piątego roku życia lub nieco później, zwykle kontynuowane jest do około piętnastego roku życia. Bez tego leczenia dziewczynki z TS byłyby średnio o 20 cm niższe, niż kobiety bez TS.
W niniejszym artykule badam biosocjalną pracę hormonu wzrostu i jego cel. Prezentuję działanie nadziei związane z leczeniem hormonami. Jest to rodzaj technologii, którą można elastycznie dostosowywać. Z mojej perspektywy hormony są „obiektami płynnymi". Przedstawiam codzienne reżimy i regularne kontrole biomedyczne podyktowane leczeniem hormonem wzrostu, opisuję prywatne i publiczne historie terapii tym hormonem oraz analizuję doświadczenie istotności hormonów, koncentrując się na urządzeniu do wstrzykiwania.

Keywords: growth hormone, Turner Syndrome, technology, materiality

TURNER SYNDROME, AN INTRODUCTION

Turner Syndrome (hereinafter referred to as TS) is a condition that affects only women and involves a partial or complete absence of the X chromosome. It is estimated that 1 in 2,000–2,500 people are born with TS in a population (Gawlik *et al.* 2013), which means that there are approximately 10,000 women and girls with this genetic disorder living in Poland. These data are only estimates as no national register of persons with TS exists in Poland.

Physical- trait- characteristics of TS include most often short stature (without hormonal therapy women with TS are on average 20 cm less in stature than those without TS[1]), low set ears, low posterior hairline, small fingernails as well as the possession of a flat, broad chest (Gravholt, ed. 2009; Kucharska 2019). From Wikipedia[2] and other websites from which many persons with TS have easy access to, it can be ascertained that women with TS can also have lymphedema (swelling) of the hands and feet as if a newborn, gonadal streak (underdeveloped gonadal structures that later become fibrotic), increased weight, obesity, shortened fourth metacarpal bone, small fingernails, characteristic facial features, a webbed neck from cystic hygroma in infancy, aortic valve stenosis, coarctation of the aorta, bicuspid aortic valve (most common in cardiac problems), a horseshoe kidney, visual impairments, ear infections and hearing loss, high waist-to-hip ratio (the hips are not much bigger than the waist), attention deficit hyperactivity disorder, nonverbal learning disabilities (problems with maths, social skills, and spatial relations) and pigmented moles[3]. The majority of girls with TS will not have all of these symptoms but they and their families will be exposed to this information on popular websites. Therefore, over the course of diagnosis and therapy, people will not only have to face particular physical and psychological problems (Skuse 2009, Lagrou *et al.* 2006) but also something I would like to call – the effect of monsterization (see Radkowska-Walkowicz 2012 in the context of IVF children). Based on information and illustrations available online in regards to TS, the image which emerges is that of a disfigured, aesthetically non-normative person which is ungrounded in reality. In my research[4], on which more below, I have met with many

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[1] The first randomized research from 2005 demonstrated that the final height of girls treated with the growth hormone over a period of 5.7 years was 7.3 (5.7 years was 7.3 cms)cm more than those from the control group (Gawlik *et al.* 2013, 59).

[2] Wikipedia is not given here as a source of my knowledge about TS. The reference to this worldwide used encyclopedia indicates which TS image is being built through the most popular sources of knowledge, to which also persons with TS have access.

[3] See: https://en.wikipedia.org/wiki/Turner_syndrome. Access: 10.02.2019.

[4] **Acknowledgment:** I would like to thank Małgorzata Rajtar, Anna Krawczak, Ewa Maciejewska-Mroczek, and Maria Reimann for inspiring discussions, mutual support, and collaboration on the project. I am particularly grateful to all girls and women with TS, their families, and physicians who

girls and women with TS who were not physically disfigured. They were just like the rest of us – women who do not bear the stigma of a genetic disorder. In fact, many of them were taller than me.

One of the most stiking symptoms of TS is gonadal dysgenesis, in which supplementation of the female sex hormone is needed. Estrogen therapy is usually introduced around the age of 12 (Gawlik *et al.* 2013). To minimize the unfavorable effects of estrogen on long bone-growth, growth hormone therapy is simultaneously undertaken, beginning as early as just a few years of age, providing the patient was diagnosed early enough. One of the major problems for women with TS and their families, which has become apparent through conversations with people affected by the syndrome (affected directly or through the illness of their daughter), is infertility (Sutton *et al.* 2005; Świątkiewicz-Mośny 2010).

It is important to note that TS does not affect intellectual capabilities and only a small fraction of people with TS have some intellectual dysfunctions or learning disabilities (Kastrup 2009; Teilmann *et al.* 2009; Skuse 2009; Hong *et al.* 2009). However, psychologists have pointed out some psychological characteristics typical of people with TS, although they do not necessarily affect everyone (Skuse 2009). These include: ADHD or ADD in childhood and behaviour on the autism spectrum in adolescence and adulthood. Katrien Lagrou (2017) also speaks of low self-esteem as well as some emotional and social immaturity.

TS became undoubtedly a multidimensional cultural fact that has appeared in specific historical, social and geographical contexts. It manifests itself in bodies that become entangled in certain social concepts concerning issues such as gender, body, biology and ways of moving and expressing oneself. It is as much a biological phenomenon as a cultural one. Moreover, TS can be seen as a lens, through which one can look at various social phenomena, such as education, womanhood, medicalization etc. TS also challenges anthropology and its key dichotomies, including nature-culture, essentialism-constructivism, nature-nurture, and body-mind.

METHODS

In this article, I would like to look at the biosocial work of the growth hormone, one of the most important actors in the lives of TS girls and their parents. My main research questions are: What is the purpose of the action and giving of growth hormone? What is its social role?

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agreed to participate in this project. The research is funded by the Polish Ministry of Science and Higher Education/National Program for the Development of Humanities (grant No.: 2bH 15 0137 83).

The research presented here is conducted as part of a Turner Syndrome research project: *Socialization patterns and the management of the embodiment in chronic disease. An interdisciplinary approach*[5] by scholars associated with the Childhood Studies Interdisciplinary Research Team, University of Warsaw. Our research includes TS women as well as their families and specialists who work with them, such as nurses and doctors as well as activists involved in TS support groups. The main tools that were used are classical anthropological methods which include in-depth interviews and participant observation. In situations where our subjects are children (girls with TS), depending on the interviewee's age methods that were more age-appropriate were used (see Maciejewska-Mroczek 2018). Additionally, we participated in summer camps and other activities organized for girls with TS. Our research is based on multi-sited ethnography (Marcus 1995), in which we not only examine the phenomenon as a complex network of dependencies, but also try to see its connections with other phenomena. Discourse in regards to TS was analyzed, all the while observing Marcus' postulate to be mindful of where a subject may take the researcher and be ready to follow. Analysis was also conducted of websites related to TS, press articles about TS as well as mentions of it on TV and in film.

In reference to this article, particular significance must be attributed to the in-depth ethnographic interviews with 21 people with TS, 10 physicians working with people with TS and 19 TS girls' parents which were conducted. Participant observations were made during training sessions for TS girls and their parents on the administration of the growth hormone, meetings of the Coordinating Team supervising the use of the growth hormone (which decides when to induct a patient into hormone therapy), as well as three summer camps organized by the Warsaw office of the Turner Syndrome Patients Support Society for girls with TS.

As many researchers were involved in the project, investigator triangulation was used (Denzin 2006). This did not mean only a division of labour, but rather a systematic comparison of the findings and results of research, and exploring how diffrent researchers influenced the field. All collected materials were shared among the research team members. Our findings were presented and discussed during team seminars, organized every week. Data from different sources – including in-depth interviews, semi-structured interviews, participant observation, and discourse analysis – was triangulated.

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[5] The research is funded by the Polish Ministry of Science and Higher Education/National Program for the Development of Humanities (grant No.: 2bH 15 0137 83). The research is conducted by M. Radkowska-Walkowicz (PI), A. Krawczak, E. Maciejewska-Mroczek, M. Rajtar, M. Reimann.

THEORETICAL BACKGROUND

The starting point of my research is constructionist theory indicating the social dimension of illness and corporeality. From this perspective, hormones are constructed in social relations, and in discursive acts. As social actors, hormones affect the girls with TS in indirect ways, via language and social constructions. However, in my research, the biological and medical dimensions of hormones' work are very important, too. Thus, while still appreciating the value of social constructionism as a theoretical orientation, I propose to perceive TS and hormones in accordance with the paradigm of new studies on materiality (e.g. Barad 2007, Coole and Frost 2010), which emphasize the role of objects in the social structure of the world. They state the need to address objects, including human bodies as well as parts or substances belonging to them, as important actors, thus moving away from a language-centric perception of reality. It is not all about naively returning to deterministic concepts of existence. As Sari Irni indicates:

> "According to the new materialists, what is needed is a new account of biology, which understands it as actively producing variations in society, instead of merely linking it to the notion and critique of biological determinism" (Irni 2013, 41–42).

In this context, TS becomes a multidimensional experience of the body and language, an action of hormones and the gazes of other people. It is a chromosomal, hormonal and social phenomenon. Although I emphasize the social nature of disability, illness, and bodily condition, I underline the biological significance. Thus, it can be seen that TS is a bodily-social phenomenon and a biopsychosocial reality. However, I am not set on treating biology solely as an external fact but rather as a certain entanglement in social processes. What is social can provoke the biological and the biological, in turn, affects social positions (Irni 2013; Roberts 2007).

ON HORMONES

The concept of hormones as a substance regulating physiological processes was developed at the beginning of the 20th century (Tata 2005). It was fundamental in changing the way of thinking about human beings and the way their bodies function (Medvei 1982). In the 1920s, hormones became the fundamental chemical signaling agent, and endocrinology became an important scientific field. Hormones, as such, have had quite a successful career in the 20th century. In fact, Ilana Lowy calls the 1920s, 30s and 40s "the age of hormones" (2019) and compares their significance to that of genes at the beginning of the 21st century. It is my belief that along with genes, hormones can be considered the most significant biosocial agent that has decisive power over our bodies, social relations, our place in the world and happiness. What is more, from an anthropological point of view, hormones are far more interesting than genes. Although genes are perceived as a solid determinant, they are unchangeable and non negotiable (Le Breton 2004) whereas hormones are “fluid objects” (Sanabria 2016; de Laet and Mol 2000) that allow human interference. Genes are stable while hormones have incredible mobility. They are responsible for sex differences (Roberts 2007), for mood and behaviour. They exceed the boundaries of body where they behave in a particular manner and for example find their way into the water supply. They induce particular actions and moral panic connected with the levels of estrogen in the water supply, which is said to decrease sperm quality. But hormones are also the world’s resident boogeyman. Chicken meat is full of hormones, which is supposed to accelerate puberty – leading to another moral panic connected with premature puberty serving as another proof of hormones’ fluidity, their unbridled and “excessive” behavior (Roberts 2015). Hormones are thus complicated and complex biosocial elements where they are a material and discursive component of the biosocial universe (Barad 2007).

There are many mentions of sex hormones in literature, particularly in feminist literature. Researchers have noted their role in gender differentiation. Celia Roberts has dubbed them the “messengers of sex” (Roberts 2007). This is very apparent in Turner Syndrome when femininity becomes questioned – one X chromosome is missing and estrogen is required to supplement it. The aim is to turn girls into women and induce a monthly blood flow out of childish, unformed and gender unspecified bodies (Radkowska-Walkowicz 2019).

We can definitely read less about the growth hormone (hereinafter GH), whose journey and mobility follow different paths than those of sex hormones. From being prescribed to short statured girls and boys hormones have found their way to bodybuilders who, today, are the main customers in the GH trade. But in either case they operate in the field of aesthetic perceptions. They serve notions of beauty and wellbeing which may be subjective but have become prescriptive in culture to varying degrees.

RECOMBINANT HUMAN GROWTH HORMONE. A HISTORY

Human GH therapy began in the late 1950s. At first, the hormone was obtained through autopsies from a cadaver’s pituitary glands. It turned out however that this process carried the risk of Creutzfeldt-Jakob disease and a search for new solutions ensued. In the early 1990s, the production of the recombinant human growth hormone (RhGH) began in laboratories employing genetic engineering methods (Ayyar 2011). The availability of using growth hormone therapy has helped patients with variying short stature problems, including girls with TS. According to our research, those, who due to time or economic restraints, were not able to benefit from GH therapy, believe that their lives could have been different had they received the hormone. They attribute many of their failures to short stature. Ewa, who was interviewed by Maria Reimann, one of the researchers on our team, is certain that her height has caused discrimination at work and is preventing her from living a happy life:

> "Short height, I am 136 cm tall and a friend of mine is about the same, 140 cm max, this is the average if you don't receive GH treatments. And well… that's how it is… we don't get a disability benefit, you need to work, to make a living, employers stare at you from the beginning… even if they don't say anything it's obvious what's going on and they don't want to hire us. Or then the things they say. I'll never forget, I haven't even entered the room properly yet and they go "but you're too short, if we had known how short you were we would've never called (…) so it's obvious we won't hire a little person. We'll take someone taller. Why hire someone little when you can take someone… prettier, no, taller. And that's how it is".

Short stature becomes crucial in how people define themselves. It is a cause for stigmatization and self-stigmatization. Maria Świątkiewicz-Mośny was right (2010) when she wrote about stigmatized identity in this context.

The beginning of GH therapy often changes the lives of people with TS a lot. According to the mother of an adult woman with TS, receiving GH was:

> "You know, like a trip to the moon, a trip to the moon. You can't describe it in any other terms, it was simply a trip to the moon".

Starting GH therapy can become a turning point in people'spersonal history. In most cases, it is a positive event and although the first shots may come with a variety of fears such as the fear of side effects as well as fear of the skin being punctured along with a child's or caregiver's fear of pain; they are also accompanied by hope. In addition, this marks the beginning of something that in the individual's private history of the disease can be considered as the onset of treatment of TS (which of course cannot be cured, as it is a genetic disorder).

The growth hormone, like most medical technologies, is a tool of hope. It allows people to believe that what is commonly referred to as "normality" (see Rajtar 2019) is within reach – although, as it turns out, it is not the only factor. At the same time it denotes another success story in the history of medicine. This means of hope makes it harder to deal with the costs that may arise during therapy. This is what happened in Marta's[6] story according to her mom:

> "Well, then it started (…) our daughter wasn't diagnosed with TS until she was 12. And that's when the whole procedure started and she was given that growth hormone (…) And it was such a shock to the system, I mean she started developing very quickly, when she transformed from a girl's body into a woman's body, developed curves, breasts, everything. She transformed from a little girl into a woman, although I think it was some kind of a shock to her body. I just don't know, a dose of estrogen and the growth hormone – in that year Marta's grades just plummeted. Not that she stopped studying,

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[6] All names have been changed.

> it's just that her potential… It's as though she was unable to take anything in. Psychological changes also appeared, she developed (…) an obsessive-compulsive disorder (…) it was as though I was unable to reach her. […] and Marta ended up in hospital for 10 months of therapy".

Personal stories are always immersed in economic and historical-political contexts. Maria's mother told Ewa Maciejewska-Mroczek from my research team about her search for a therapy for her daughter which became interestingly intertwined with the process of political transformation:

> "Just imagine, we were after transformation [after the fall of communism] and pharmaceutical companies were rushing into Poland and one of these aforementioned pharmaceutical companies was giving away GH for four patients with TS".

At first, she managed to get her daughter into a yearly GH treatment program. When that supply ended, she got lucky again as there were a tiny number of cases of mushroom-consumption related poisoning among children for whom there was a reserve of GH – as she told us – and there was enough GH for her daughter for another six months. When it seemed that the therapy would have to come to an end, the family received support from a German foundation. Working in the West, Maria's mom was able to earn money for more growth hormone injections.

> "I did not get the hormone but a promise of money, as it was possible to buy GH at the Children's Health Memorial Institute. I received 300 million Polish zloty. I packed it into a plastic bag, took my then-partner as security and said'let's go'. I withdrew the money from the cash desk at the embassy and we went to the Institute to make the payment. And of course there was a little cashier window with a female cashier and I just pushed the bag towards her and said: 'here you go, that's 300 million for the growth hormone'. She licked her finger and started counting. Everything was in order. That was back when a cashier would take a pencil and write out 'deposit accepted' on a small strip of paper and she wrote down that she accepted 300 million Polish zloty because I needed to have proof that the money went where it was supposed to go".

A turning point occurred in 2000 when the Ministry of Health began to reimburse growth hormone therapy for girls with Turner Syndrome in Poland who fulfilled clearly defined clinical criteria (Świątkiewicz-Mośny 2010).

THE MATERIALITY OF THE RECOMBINANT HUMAN GROWTH HORMONE

A plastic bag filled with money serves to demonstrate that the success of GH can be attributed to many agents, human and non-human. Apart from people who work in labs, there are also the mothers, their bodies and the finance involved. Nowadays the therapy is reimbursed, someone else is busy carrying bags filled with money and the very existence of these bags is questionable today. Other forms of tangible objects are important today, such as the stack of papers and documents that need to be handed in to the Coordinating Team Committee on Growth Hormone Treatment at the Children's Health Memorial Institute in Warsaw. Details which need to include personal contact information, precise biomedical measurements, family history and pregnancy history, all which need to be supplied in a standardized request form submitted to the committee:

> "Applications that do not at least contain a karyotype description, TSH, fT4, and IGF-I levels, carbohydrate metabolism evaluation, as well as x-rays for bone age assessment, cardiovascular, abdominal and pelvic imaging and growth charts will not be considered"[7].

However, when the requirements put forth by the Commission for the future beneficiaries of the GH are met, a daily routine begins, marked by regular injections into various body parts. GH must be stored in a fridge and injected every night in a very specific manner which is taught at the hospital. Every three months the patient reports for follow-up visits where the doctors take precise body measurements, particularly height. Hormone levels are verified and most importantly, empty GH ampoules will be counted and a new dose will be issued for the following months. In order for the therapy to continue, the body must be responding to the hormone (it needs to grow).

Each shot for our respondents and their parents represents hope for additional millimetres in height. And it would seem that every millimetre is of utmost importance. Despite the absence of unambiguous indications that it can be of therapeutic significance, some parents keep their daughters at home from school trips, even two-day ones, if there is the slightest doubt that the administration of the hormone could become a problem. Others try special diets. The parents that we met during our research were much more detailed in carrying ou the therapy than the doctors, although doctor informed us about many patients who did not follow their recommendations. Perhaps, that is why a doctor who was instructing a daughter and her mother in one of the hospitals emphasized the possibility of stopping the injections for a short period of time. In a note from another observed training I wrote:

> "It seems that doctor gives a little less information about side effects, but some still are noticed. Everything is OK. There's mention of school trips but Dr. X is focusing on saying that it's worth considering if they ought to be missed. Sometimes people need to consider if going somewhere is more important socially than hormone injections. But it can't happen too often. It is important to take the doses. The doctor isn't talking much about access to a fridge and the things which can be organized. According to the doctor it all boils down to either injecting or going on a trip".

Some of our respondents never went anywhere. Others always did. Teenager Mariola, who could never imagine missing a dose, went on school trips but hid the fact that

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[7] The application is available here: http://hormonwzrostu.czd.pl/index.php?option=com_content&view=article&id=99&Itemid=79. Access: 10.09.2019.

she needed to take injections from her peers. She did not reveal her illness. In another case, described below, the opposite happened where the illness was hidden by being in plain sight. Nonetheless, today the hormone is far less visible as its tangibility and bio-medical origin are hidden away in an injection pen. Ewa Maciejewska-Mroczek wrote in a note from a summer camp:

> "We are talking to Ewa about heating the pen, something I heard about from Justyna, Iga's mother, in that it should be removed from the fridge sometime before the injection. Ewa says this is one of the new myths about administering GH, which wasn't around back in her days. She talks about 'her days' a little and how she started out with normal syringes with a long needle, then a shorter needle. She recalled that for some time there was an awkward needle free device that pushed the hormone through the skin using high pressure (it caused nothing but problems and she failed to administer properly a dose three times). Lastly she had an injection pen, much like the ones being used on this trip".

The transition from a thick-needle and a syringe to a delicate injection pen, just as in the case of other medical technologies, can be described as a process of miniaturization, normalization, obscuring/concealing[8] and blurring the boundaries between technology and the body and its everyday reality. Something crass and bulky (emphasized by Maria's mom in her story about a plastic bag and thick needles) transforms into something more delicate. A wad of cash has turned into a transfer of information and medical documents. From obtaining the hormone from pituitary glands of cadavers we have moved on to recombinant DNA in a lab employing specialised genetic engineering.

Pen injector case (photo: E. Maciejewska-Mroczek)

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[8] Of course not always does the shift occur from the visible to invisible: estrogen tablets are increasingly frequently replaced with patches and therefore a great example that sometimes the opposite happens.

A thick needle has been replaced with a thin needle. A syringe has been replaced with an injection pen that hides the fact that it represents medical technology at all.

The young patients that we have met during our research, are following the intuition of pen and growth hormone producers, who know that daily entanglement in medical procedures should be habituated. Hence, injection covers are decorated in pink unicorns, hearts and cats (see photo 1). Technology, according to the cover of a well-known book *Care in Practice: On Tinkering in Clinics, Homes and Farms* (Mol *at al.* 2010), is not the opposite of care. It "is not cast as a functional tool, easy to control – it is shifting, changing, surprising and adaptable".

HEIGHT

Growth is a key issue in Turner Syndrome, which in itself is incredibly interesting. Some other symptoms of the syndrome become socially invisible, while others play no significant role in the personal and public stories of the patients. The issue of height and growth hormone therapy in nearly all forms of communication – be it Wikipedia, medical textbooks or personal stories – is key and appears centre stage. Nowadays somatotropin therapy is able to provide girls with a height that is often close to average. Nonetheless "low" height is still prevalent and is perceived as the main problem of people with TS. One of our interlocutors said:

> "It was apparent that at first the only thing I really knew about the Syndrome was that I will be short! And that I will need to take growth hormones. That was the knowledge I started out with. My parents explained something about it by stating that there was something wrong with my genes".

Anna Krawczak, from my research team writes:

> "Interestingly, despite these fundamental clinical and social variables, the theme of height in their narratives remains just as important as in conversations with women with short stature. The danger of short height – actual or internalised is the fear of a prophecy that may come true – which constantly appears in the girls' narratives (…). Getting the girls and teens accustomed to the issue of short stature is a significant part of pamphlets and studies by patient support organizations although since 2000 supplementary therapy covers each short statured girl with TS. The parents of girls who receive GH supplementation raise concerns about their daughters' short stature and their future in the context of physical dissimilarity" (Krawczak, forthcoming).

People with TS are often perceived as out of place to some degree. Too short, too small, initially too fast, then – during puberty – too slow. One of the mothers told us about her now adult daughter:

> "She has these little legs and weaker muscles. Aside from that, her legs are so short. Her body is not entirely proportional. She has long arms, a long body and quite short legs".

Some of our interlocutors find this peculiarity difficult to identify. It is not always apparent whether this peculiarity really pertains to differences in the behavior of TS girls and women or whether it is a reflection of complicated relations where family, biomedicine, school and social expectations towards women's bodies all meet.

Małgorzata Rajtar has noted:

> "It turns out that the use of GH serves not only as an improvement on the metric scale but is rather a strategy for reaching a state of 'normalcy' which would allow for equality of treatment in social and professional relations and in effect, for instance, would increase people'schances of landing a job that matches their qualifications and to establish peer and romantic relations" (Rajtar 2019).

The main tool that supports the notion that it is necessary to grow is the growth chart. It is the dream tool of modern biopolitics and Foucauldian power-knowledge. It is a tool for disciplining parents and children alike and a way of controlling the human body through "unhuman biomedicine". Mothers are particularly disciplined in this case. They are trained to do this from the moment of childbirth – it is clearly visible when analysing the discourse and practices concerning the feeding of newborns (see Sachs *et al.* 2006; Radkowska-Walkowicz 2014). A child's weight and height projected onto a relevant chart have become an indicator of good or not good enough motherhood.

SECRETS AND UNDERSTATEMENTS

And yet, the growth hormone which is supposed to satisfy the requirements of a growth chart can also be used for other purposes. Anna Krawczak (forthcoming) points out that this focus on growth is only part of broader processes concerning TS girls connected with infantilization and socialising to disability. In my opinion, another function of measuring height and the GH itself is more important in covering other problems. This is perfectly evident when we examine TS from the perspective of secrecy and furtiveness[9]. Girls are usually informed they have a genetic disorder called Turner Syndrome once they begin their growth hormone therapy. That is what happened in Klara's case:

> "[B:] Klara, do you remember how it happened? Did you even know what was happening then or were you too young?
> [R1:] Not really because no one wanted to tell me.
> [B:] Aha. Maybe at first your parents were protecting you a little from this information, no?
> [R:] Maybe yes, she didn't ask much, we didn't tell her much, there was no…
> [R1:] I only knew that I had to take some kind of shots and that's all I knew"
> (interview with an 18 year old and her mother).

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[9] I am referring here to an idea of Ewa Maciejewska-Mroczek, which was presented during a conference *Secrets, half-truths, understatements. What is said and what is left unsaid around children?*, Warsaw 2018.

At one of the summer camps, our researchers were observing relations between Justyna and Iga. The mother admitted about her five year old daughter:

> "Right now she sort of knows that something is going on but she doesn't really know what it's about, she doesn't know at all. She knows she's taking a hormone".

In her research journal Anna Krawczak describes the following situation:

> „'Iga, tell the lady what your biggest problem is'. I was surprised because from our conversation it transpired in no way am I interested in 'problems' or that I perceive TS as a problem. […] Iga became embarrassed and hugged her mom and the question was repeated, again without the child reacting. Then the mother said 'Iga's biggest problem is her short height'".

The question of what to tell children with TS and when to tell them the truth about the illness is a recurring topic in our interviews. TS girls and women agree unequivocally that children should be informed as early as possible. Also, psychological research demonstrates that not informing children about their TS may have negative effects on their psychological development (Lagrou 2017). Still many parents choose to delay sharing this information. Paradoxically the growth hormone is an ally in this secrecy. Children find out they have to visit doctors and that they have to take shots due to their short stature. The problem of infertility and other possible setbacks resulting from TS as well as the fact that we are dealing with a genetic disorder are delayed in time by parental concerns. I agree with Anna Krawczak who writes:

> "The growth hormone helps to deal with the main visible distinguishing feature of this condition, while, at the same time, it does not require the use of dangerous terms such as: *Turner syndrome, genetic syndrome or illness, disorder.* However, this does have side effects. Together with the growth hormone, the girls' bodies are injected with fear of otherness and the conceptualization of this otherness, as symbolised by short stature".

But looking at how GH works in a social space, one also has to note that it changes daily habits and rituals. This daily regime includes the right injection time, the right injection location, correct storage of the hormone and ofempty ampoules. It is interesting that the responsibility is discreetly shifted onto the patient (or her mother) which is not surprising in the context of modern medical practices and the culture of individualism (Nowakowski 2015, 103–112; Jacyno 2007). I saw it clearly during growth hormone injection training.

> "A lot depends on you, girl – the doctor says convincingly. How much you'll benefit from it, is entirely up to you. The next two years are key, well the next year actually. You need to take this every day, before going to sleep. (…) I can tell from your mom's face that it won't be easy. I know, says the doctor, homework, etc. Yes, the mom confirms. But it is important. And she needs to fall asleep at 9:30 pm at the latest, explains the doctor. It's not just about the certain amount of hours of sleep required but also about going to sleep early and getting up late. It's important to be sound asleep before midnight. 'You grow when you sleep – it's been proven'. Period".

Therefore the final result depends on a person's response to what advanced medical technology has to offer. This technology, the growth hormone, is not external to the patient and her family. Positived results arise when accompanied by good care (Mol *et al.* 2010) and some self-discipline. In many contexts, the existence of this technology may also have negative social results, such as strengthening the belief in non-normality or even in the disability of short statured people (Murray 2008) as well as rare side effects the body experiences, something that is mentioned to the parents of children who are starting GH therapy and also during GH injection training. However, appropriate synchronization of technology and embodied person, technology and care leaves no space for discussion on the point of GH treatment as a body enhancement technology. As Linda F. Hogle points out:

> "Enhancements exist in a nexus of complex social, political, and historical relations, media representations, and medical and legal definitions of disorder and well-being." (Hogle 2005, 696; see Rajtar 2019).

Małgorzata Rajtar notes:

> "In striving for additional centimeters, which in fact represent an opportunity (perhaps an uncertain one) to live a fuller and more dignified life, ethical considerations, such as the inability of the little girls who undergo GH therapy to provide informed consent (…) and questioning the point of the therapy itself due to its duration and costs (Murray 2008) get pushed aside" (Rajtar 2019).

CONCLUSION

What then is the purpose of the growth hormone and what is its social role? It helps in the growing process, in positively responding to the requirements of growth charts and in meeting subjective perceived beauty standards. It can thus help in achieving what is subjectively defined as "normal". It also helps in avoiding discussing Turner Syndrome and redirecting everyone's attention to the issue of height. It also changes everyday habits, rituals and through the necessity of regular checkups it becomes a longer lasting presence in TS women's relationship with biomedicine. The growth hormone defines another success in the history of medicine and provides bio-ethicists with incentives to ask questions about the ethical side of therapy and body enhancement, while providing ethnographers with incentives to ignore it.

The growth hormone is the promise of a better future. It is also a tangible product that belongs to the body but has to be delivered from the outside. It is a fluid, mobile object, supporting various discourses and aspirations.

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