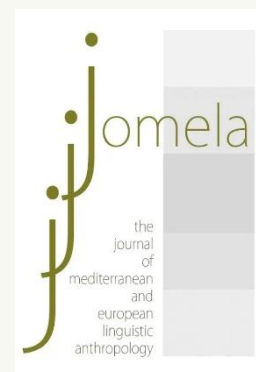


Navigating Identity Dilemmas in Oral Narratives by Women with Turner Syndrome

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Mediterranean and European
Linguistic Anthropology
2022, Vol. 4(3): 30-49
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DOI: 10.47298/jomela/v4-i2-a3
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Abstract

Turner syndrome (TS) is a genetic disorder that affects only females. Its main symptoms are a short stature and gonadal dysgenesis. Such genetically determined physical characteristics impact the positioning of TS women in discourses of femininity, health, and illness, as well as in social relationships.

This study aims to uncover and explore the social identities of women with this condition. The analysis draws on premises of 'the narrative practice' framework developed by Michael Bamberg (1997, 2005, 2011, 2012, 2020) who claims that in interaction, narrative is not only used to convey meaning, but also to construct the identities of the interlocutors. The linguistic analysis of narratives delivered by Polish women with TS in semi-structured interviews should reveal the extent to which the interviewees enact the creation of or become their identities, the extent to which they align with or distance from others, and the extent to which their identities change or remain constant over the years of hormonal therapy. We draw on functionalism to discuss these narratives, in which their formal structure and content are integrally associated with their use.

Key words: *Identity, narratives, Turner syndrome, Poland, linguistic anthropology*

Introduction

Narratives have been found to occur in a wide range of contexts, and can constitute an important resource that people employ to make sense of their life experiences and to construct their identities (Thornborrow and Coates 2005). Narratives can also have a key role in the location of the emergent self in social and cultural worlds, and therefore frequently appear in research to aid the investigation of the process of identity making, Bruner 1990, 1991, 2001; Chafe 1994). Bamberg (2011, p. 100) notes that narratives

apparently have moved themselves into the toolkit par excellence for personal identity construction and also for what can be called the establishment of an enduring sense of self.

This becomes the case with medical ailments, and for example Turner Syndrome. Turner syndrome is a random genetic disorder that affects only females. It is caused by the complete or partial absence of the second sex chromosome. A girl with Turner syndrome only has one normal X sex chromosome, rather than the usual two (XX). This different genetic design leads to a specific physical phenotype that includes gonadal dysgenesis, lack of pubertal maturation, infertility, short stature, webbing of the neck, coarctation of the aorta, and a horseshoe kidney (Hutaff-Lee et al. 2019; Rieser and Davenport 2019; Zadrožna 2013). While these symptoms may appear in individuals to various degrees, short stature and infertility are the key symptoms that manifest in every woman with the 45,X karyotype typical of TS. Females with TS receive life-long medication and hormone replacement therapy (HRT), to reduce the risk of cardio-vascular or kidney failure, or osteoporosis, and to induce the development of secondary sex characteristics, as well as to compensate for physical malformations (webbed neck, a broad chest), and therefore improve their social welfare. Infertility, however, is incurable in the 45X karyotype due to ovarian failure.

Turner syndrome is rarely discussed in scientific literature outside the medical sciences. One factor influencing this inhibited phenomenon is the fact that TS escapes interest from scholars in the humanities, as the verbal skills of females with TS are preserved. This preservation contrasts with other aspects, such as their cognition (visuo-spatial processes, visual memory, arithmetic) and socio-emotional functioning (facial affect recognition, social hypersensitivity, verbal IQ greater than performance IQ) which become impaired (Center for Interdisciplinary Brain Sciences Research (CIBSR) 2020). Therefore, more research emerges in psychology and cognitive sciences rather than in the human sciences. Another factor influencing the unpopularity of research on TS in the humanities might be the rarity of TS (1 in 2,500 female births), and seemingly unimpaired functioning and independence of the majority of TS females in society, thus dimming the need for deeper research on social or pragmatic competences of these subjects.

What is more, as Rieser and Davenport (2019, p. 2) note, “[e]very girl with TS is unique and no generalization will apply to every girl, no matter how accurate it is for the group,” and therefore, research on TS comprises individual case studies rather than large quantitative studies that are unlikely to yield results representative for the cohort. Nevertheless, the symptoms of TS can form the basis for the bearer to recognize herself as different, and therefore unique, in terms of bodily appearance and her prospective social roles, which, albeit infrequently, evoke interest in anthropology.

Despite these gaps in TS research, the phenomenon has received some attention in anthropology and discourse studies for at least two factors. First, the symptoms of TS can form the basis for personal identity construction and for the bearer to recognize herself as unique in terms of bodily appearance and her prospective social roles, which has evoked interest in anthropology. However, bodily abnormalities such as short stature or stunted breast growth may serve as a source of social discrimination, prejudice, and exclusion, which would likely inspire research in critical discourse analysis targeted at the improvement of the societal positioning of the underprivileged. Two notable exceptions of TS discussed outside of the medical sciences are relatively recent; one is the research conducted by Katrien Lagrou and her team (1998, 2017) in the social sciences and one is a study by Audrey Jones in anthropology (2020). In Poland, however, the issue seems to have drawn more attention from scholars in the social sciences (cf. Świątkiewicz-Mośny 2010; Zadrożna 2013; Maciejewska-Mroczek et al. 2019), but it is still absent from humanities.

Nevertheless, the research on identity practices among adult women with TS is scarce, and as TS is a multidimensional experience of the human body, society, cognition, and language, it should be addressed in the medical and social sciences as well as in the humanities. Accordingly, this article focuses on narratives that occur in semi-structured interviews when women with Turner syndrome (TS) talk about their experience of a lifelong genetic condition, in order to show how they navigate social identity dilemmas (Bamberg 2011). This article also seeks to sketch a portrayal of TS as a lifelong chronic condition that becomes a permanent part of a woman’s life and identity. My intention is not to construe TS as a set of symptoms, as is usually the case in medical reports, but as a lifelong chronic condition that becomes a permanent part of a woman’s life and identity.

Background

TS is not a disease, as such, but a random genetic disorder caused by complete or partial absence of the second sex chromosome that affects only females.

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, p. 122)

This variant genetic design leads to a specific physical phenotype that includes gonadal dysgenesis, lack of pubertal maturation, infertility, short stature, shield chest, webbing of the neck, coarctation of the aorta, horseshoe kidney (Hutaff-Lee, Bennet, Howell, and Tartaglia 2019; Rieser and Davenport 2019; Zadrożna 2013). While these symptoms may be displayed in individuals in various degrees, infertility and short stature are the key ones that manifest in almost every TS woman with the typical karyotype 45,X.

Females with TS require life-long medication in order to reduce the risk of cardio-vascular or kidney failure and osteoporosis, as well as to compensate for physical malformations like short stature. Although the medication, hormone replacement therapy (HRT), is considered beneficial from both medical and psychological perspectives, TS women are deeply concerned about a number of issues related to HRT. Amongst these, acting as an agent in the process of medication rather than merely a recipient of HRT and thus erasing social boundaries developed solely on physical differences are crucial and require deeper investigation. What is more, in Poland, growth hormone (GH) therapy was by and large unavailable to TS women whose puberty fell prior to the year 2000. Therefore, differences in identity construction between the TS women who received GH therapy and those who did not can be anticipated.

Methodical Framework

For some narrative inquirers of identity (Bamberg 2011, 2012, 2020; Bruner 1991; MacIntyre 1981; Polkinghorne 1988), the narrative has become a privileged genre in that, as they claim, life has narrative-like tendencies and people enter the narrative mode at times when they aspire to reflect on their life or to bring coherence to it. Bamberg (2011) argues that narrative has a special status in identity construction, as it enables positioning of a sense of self in relation to culturally shared values and existing normative discourses.

Through telling stories, we disclose ourselves. Narrative may have a key role in the location of the emergent self in a social and cultural world (Bruner 1990, 2001; Chafe 1994). Analyzing narratives that women with TS can disclose during talk, we may see how they construct their medicalized self and how this self may become entangled with their healthful identity. My aim in this study is to investigate the ways in which these women navigate the agency-recipientcy

dilemma (Bamberg 2011), positioning themselves within discourses of health and illness, and the ways in which GH therapy or its lack affect the resolution of the sameness-difference dilemma (Bamberg 2011) from both diachronic and synchronic perspectives.

In this article, women with TS narrate their lives and position themselves and others in discourses of health and illness, while shared systems of values and social norms refer to those prevalent in Polish society. I examine the stories the individuals with TS tell as they discuss their experiences with TS, to determine, through their narratives, how they integrate the experience of living with TS into their life story and make the everyday details of coping with TS part of their sense of the kind of person they believe themselves to be. The starting point of the analysis is “the who-are-you question, which is deeply woven into and abundantly present in mundane situations of everyday interactive practices” (Bamberg 2011, p. 103). This question, however,

does not presuppose a unitary subject as the ground for its investigation. Rather, the agentive and interactive subject is the ‘point of departure’ for its own empirical instantiation (Butler 1995: 446) as a subject that is constantly seeking to legitimate itself, situated in language practices, and juggling several story lines simultaneously.

(p. 224)

Navigating the starting point as the first dilemma, speaking subjects position this “who-they-are in terms of some form of continuity, constructing their identities in terms of some change against the background of some constancy (and vice versa)” (Bamberg 2011, p. 104). Navigating a second dilemma, the speaking subject is viewed “as a bodily agent (i.e., as bodily present in situ and in vivo and interactively involved) (Bamberg 2011, p. 106) who either actively engages in narrative practices and positions story characters as in control or controlled by the actions of other interlocutors and/or cultural forces (Bamberg 2020). Navigating the third dilemma, speakers align or position themselves in contrast to individual or group.

Thus, it is typically through discursive choices that people define synchronically a sense of (an individual) self as different from others, or they integrate a sense of who they are in terms of belonging to particular communities of others.

(Bamberg 2011, p. 105)

These spaces of identity navigation mentioned above are dilemmatic, because storytellers make choices of linguistic, rhetorical and discourse devices; and these choices are analyzable in the storytelling interactions. Thus, the ways in which information is encoded, structured, and communicated become relevant not only for the effect of the story on the audience but also for identity construction and navigation of the speaker.

In this study, I draw on the classic definition of a narrative unit from Labov and Waletzky's (1967) framework. This framework describes the narrative as composed of at least two Complicating Action clauses that "constitute the propositional strand of meaning" (Cheshire and Ziebland 2005, p. 21). Equally essential to the narrative is Evaluation (Labov and Waletzky 1967; Labov 1972), which reveals the narrator's feelings regarding the events s/he is recounting, justifies the telling, and "establishes the kind of self that is presented" (Linde 1993, p. 81). The analysis of narrative within the Labovian framework "integrates the sequence of events (as intended or not-intended) into more or less coherent configurations that contain a purpose" (Bamberg 2012b, p. 82). By analyzing the structure of events in the story, and the construction of characters, I can make inferences about the identities that the author of the story aims to fashion.

The study of narrative structure is only one aspect that should be considered during an analysis in identity research. Equally important, as identity analysts (Bamberg, Bruner) argue, are 'narrative practices' (Bamberg 2012a,b, 2020), i.e, the manner of incorporating and using narrative in interactional contexts. Narrative analysis in identity research, therefore, must be conducted on two story levels or

realms: (a) the realm of experience, where speakers lay out how they as individuals experience certain events and confer their subjective meaning onto these experiences; and
(b) the realm of narrative means (or devices) that are put to use to make (this) sense
(Bamberg 2012b, p. 77)

I combine these subrealms with storytelling practices, as each is a space to analyze positioning.

First, storytellers position characters vis-à-vis one another in the story they tell. Simultaneously, they position themselves vis-à-vis their interlocutors in the process of telling. Third – and this makes storytelling particularly interesting for identity researchers – storytellers position themselves vis-à-vis dominant master storylines/discourses and thereby convey a sense of who they are – to their interlocutors and to themselves.

(p. 244)

Only by combining linguistic and thematic structuring with the situated performances of the narrative, can I, as analyst, extrapolate the positioning of the actors from the local contexts to larger and possibly master discourses. Furthermore, positioning presupposes agentive speakers or storytellers who not only provide a sense of who they are in interaction and dominant discourses, but also navigate the constructions of characters in three dilemmatic spaces: sameness/difference, agency/reciency, continuity/change (Bamberg 2011, 2012, 2020).

In the article I will thus present a micro-analysis of short segments of interviews with women with TS in which narrative patterns can be found. I will observe how the interviewees position story characters vis-à-vis one another (Level 1 analysis) and how they position themselves vis-à-vis the interviewer (Level 2 analysis), to finally address the issue of how the TS women position a sense of who they are in capital-D discourses of femininity, health and illness and social relations (Level 3 analysis). I will also analyze how they navigate the three dilemmas by constructing their identities in terms of change against the background of some constancy, by affiliating and aligning themselves in terms of group membership and seeing themselves as same or different, and by presenting themselves and characters of their stories as responsible “for success and self-aggrandizement versus denials of culpability in mishaps and wrongdoings” (Bamberg 2012a, p. 205).

I take the data from a series of interviews by Kamila Ciepiela, as a part of the project “Disability Studies in Humanities” launched and funded by the State Fund for Rehabilitation of Disabled People in Poland. Ten adult Polish women with TS participated in the study. Of these, the stories of three women will be analyzed. The interviews were conducted in Polish, audio-recorded, transcribed and translated to English with a simplified transcription convention adapted from Jefferson (2004). The three interviews for the analysis in this article were selected at random. These interviews were semi-structured in the sense that each began with a request directed at the interviewees to define Turner syndrome, and closed with two evaluative questions about the impact of TS on the real and possible (future) selves that the interviewees may perceive. The opening question sought to embed the talk in a discourse of Turner syndrome, while the closing questions targeted the core subject of the research, namely identity construction by TS individuals.

In these interviews, the research context has been approached with the purpose of observing whatever may be present there, and allowing further questions to emerge from the context. Semi-structured interviews are less rigid, and the researcher uses a list of questions as a guide, while still having the freedom to digress and probe for more information. Interviewers can develop and adapt their own questions, helping respondents to open up and express themselves in their own terms and at their own speed. Semi-structured interviews are more similar to natural conversations, and the outcomes are not limited by the researcher's preconceived ideas about the area of interest. Mishler (1986) points out that narratives occur frequently during interviews if interviewees are given room to speak. This is the case in the interviews conducted with the women with TS.

In terms of narrative structure, the organization of the interview is reminiscent of Russian dolls, i.e. the opening request constitutes a frame and other “stories contained in it are recurring elements that may nest inside each other” (Fludernik 2009, p. 29). Lower-level narratives

provided by each interview participant may also become frame narratives that are told in parallel, without any explicit reference to verticality. An example of such horizontal framing may become an account of diagnosis, growth hormone therapy, school harassment, or employment discrimination. The closing questions generate the narrowest frame narrative, and one that portrays the character of the teller herself against a backdrop of Turner syndrome characteristics.

This qualitative research follows an inductive path that begins with few perceived notions such as short stature, gonadal dysgenesis, or hormone substitution therapy, followed by a gradual fine-tuning and narrowing of focus on TS female identity construction. It strives to present an emic perspective of TS identities with the categories and codes for analysis being derived from the data themselves rather than being imposed from the outside. Here, the study began with few perceived notions such as short stature, gonadal dysgenesis or hormone substitution therapy, followed by a gradual fine-tuning and narrowing of focus on TS female identity construction. It strives to present an emic perspective of TS identities with the categories for analysis being derived from the data themselves rather than being imposed from the outside. The narrative analysis should thus reveal how women with TS:

- employ narratives to integrate TS in their self
- navigate and perform their identities in interviews,
- solve agency-recipientcy, sameness-difference, and continuity-change dilemmas,
- differ in self-positioning and being-positioned orientation depending on whether they received GH supplementation.

Analysis

Lucy

Lucy is a 26-year-old PhD student of philosophy. She was diagnosed with TS in her mid-childhood. At the time of the interview, she was completing her PhD in philosophy. She lived in an apartment in a big city in Poland with her younger twin-sisters, with whom she shared daily house chores.

1.	Interviewer: erm if you were to say that, would you be a different person without TS?
2.	Lucy: I mean I think it's part of my personality and sometimes when I look at myself, I don't know what I have after my mom who is very expressive, erm who is a choleric, and I wonder how much of that is a question of personality, because I notice the features of my mother [crying, wiping her tears with her index finger], because when I feel frustrated or I don't like something, I rush to my mum, but on the other hand I see that my behavior [crying ceased], it is

	related to the therapy, for example my sisters noticed [crying again], because I'm on patches, that I forgot to put [the patch]=
3.	Interviewer: [mhm]
4.	Lucy: I don't know, and I can cry all Sunday, everything irritates me, and then it turns out, you definitely didn't stick that patch or something and it's strange, but I have an impression it is all connected somehow
5.	Interviewer: mhm
6.	Lucy: I have a bit of an approach from special education, I went to a conference in WXXX for people with disabilities and gave a paper on TS, I feel good about it, it's a bit like my world, when I see all these disabilities, it's so normal for me, I feel good I feel part of
7.	Interviewer: so not only TS, but also other disabilities, you empathize with these people
8.	Lucy: yeah

Responding to a question through which we aimed to close the interview, Lucy delivers two small stories. In the first, which can be titled 'Estrogen patch,' there are three human characters, Lucy and her younger twin-sisters, as well as an inanimate character – the patch. Lucy forgets to stick the patch, and as a result, she is tearful all Sunday. Her sisters who function as one character and speak one voice notice the absence of the patch, and remind Lucy that she should stick it. The activities performed by the sisters, being a part of the 'complicating action' component of the narrative, instigate certain actions performed by Lucy while her actions that develop in 'resolution' are reactions to the verbal suggestions made by the sisters. Proactivity of the sisters is revealed not only from their role of the main characters in the 'complicating action' (Labov and Waletzky, 1968), but also from the semantic function of agents they play in the propositions. They find the reason for Lucy being tearful, and indirectly supply a solution to the problem (2, 4). Lucy, on the other hand, playing a key role in the 'resolution' (Labov and Waletzky 1968) is a reactive beneficiary of the actions performed by her sisters. Moreover, Lucy, framed as a reflective character (2, 4), more often than her sisters, provides 'evaluation' (Labov and Waletzky 1968) of the actions performed by each character. Yet, when compared with her sisters,' Lucy's evaluation, albeit delivered more frequently, is less conclusive than the one provided by her sisters. She employs verbs in the present tense that label mental processes and states (know, notice, see, think), and therefore her reasoning, by analogy to philosophical reflection, can be subject to challenge and revision. In contrast, the evaluation provided by Lucy's sisters which draws on tangible evidence and verbally strengthened with an intensifier (4) is irrefutable.

Although the inanimate character, the estrogen patch, semantically seems to be a patient of Lucy's actions, in reality, it is the patch that has control over her condition. If she does not stick it, her mood changes; she becomes anxious, irritable and tearful, which is socially inappropriate.

When the patch is placed, Lucy's behavior meets the norm. Hence, the hormone "can be considered the most significant biosocial agent that has decisive power over [Lucy's] body, social relations, [her] place in the world and happiness" (Radkowska-Walkowicz 2019, p. 17). When the patch is applied, tearfulness, the most visible mark of TS, disappears, which makes Lucy 'invisible' and fitting the world of the non-impaired.

The sameness-difference dilemma is dealt with in the second story (6). Lucy recounts an event of a conference in which she gave a speech on TS. In the story, she is the only overtly depicted single hero while the presence of other characters is implied and can be reconstructed on the basis of a common mental script of a conference which includes multiple presenters and participants who meet to discuss specific topics. The other characters in the story form a fairly cohesive group meeting one criterion – having a disability, and in the coda of the story Lucy explicitly says that she feels a part of that community (6). In this story, contrary to the Estrogen patch, Lucy is an agentive character who intentionally takes part in the conference. Semantically, the story character is an agent and an experiencer who not only receives the information from the environment but also consciously deliberates over the situation and her own feelings. Lucy evaluates the event and its participants as normal, which, along with two other evaluative phrases and an explicit back-channel confirmation in the following turn (8), further evidences that TS is a part of Lucy's identity that marks her off as different from other typical women, and enables her to align with those who are socially marked as disabled.

Maria

Maria, a 52-year-old divorced woman, was diagnosed with TS in her early childhood, and later, in adolescence, with severe osteoporosis and arthritis. She never received GH supplementation, and as a result her height reached 134 centimeters. She graduated from a secondary school for people with disabilities, used to work as an engine winding machine operator, and at the time of the interview she received a disability pension. She lived on her own in a medium-sized town in the West of Poland.

1.	Interviewer: How would you say in your own words what Turner Syndrome is?
2.	Maria: Oh, well, not an easy disease and difficult to diagnose and difficult to live and survive. Well, sometimes it's difficult to live with it, and sometimes not, sometimes you like it, and sometimes it's fun, sometimes there're funny situations. Well, I found myself in such a funny situation when I got married. We're traveling by train, and that is why I didn't wear a wedding ring after that, because when we're going out or when I was going somewhere on my own, and once at the butcher's, a lady says, oh, a child's wearing a wedding ring. Good, I came home pissed off, I took off the wedding ring, 'I won't wear a wedding ring if they say that the child's

	wearing a wedding ring.' Back then, when I was traveling with him [ex-husband] I wore the ring, but the clippie did not see it. We didn't manage to buy tickets at the ticket office, or it was closed, I don't remember, and he says to the clippie two tickets please, and the clippie looked at me and said, 'one ticket, and buy an ice cream for the child instead' [laughs]. And we left the train and I said to him, 'now you have to buy an ice cream for the child [laughs] no excuses!'
3.	Interviewer: But you rather took that as [laughable]
4.	Maria: [Yeah, as] funny
5.	Interviewer: You didn't feel offended by that, did you?
6.	Maria: No, as ordinary, as I say, until I was thirty, I really looked like a child. Once, when I was younger, I entered an office. For example, there were such situations that I was told I have to come with someone older because they told me I would not arrange anything, because the child came. And also such a situation when I lived with him in the country, a chimney sweep came, we got married in October, and in December before Christmas, the chimney sweep came. I opened the door, and the chimney sweep asked, 'is there an adult at home? because the child can't sign documents', but I could sign, [laughs] because I knew what's going on, I mean I could sign [laughs], because I was the adult at home=
7.	Maria: =Only from the age of thirty, I looked mature, you know, wrinkles appeared in my face, every adult looks like that
8.	Interviewer: And now?
9.	Maria: Now there happen situations that, for example, a child tells her mom, oh, look what a little lady is walking. And how can she say it otherwise? Sometimes a mom scolds her child, don't say so. But how can she say it otherwise? She's telling the truth. Well, a little lady is walking, how should she say it otherwise =
10.	Maria: Oh, I also remember such a funny story in my family, I mean in my friend's family. Their three or four-year-old son was there, I think he was three, then. I went to them for a coffee for the first and last time and he was there and we're drinking coffee, and he came up to me with a toy car and asked, "will the big kid play with me?" Well, we squealed with laughter and even now I remember that.
11.	Interviewer: That is, body height is such [an experience]
12.	Maria: [not really]
13.	Interviewer: It's just that your approach is like [this]?
14.	Maria: [Well] no need to get angry. Well, these are funny stories. Well, when, I say, when someone tells a child, don't say that, and how is the child supposed to say that? It could be worse, but a little lady is ok. Well, how else to say that?

The fragment of the interview contains several stories that aim to be illustrative of the attitude that Maria holds toward her bodily appearance resulting from TS, and of the attitude of other people. Maria clearly marks a borderline at the age of thirty years when wrinkles first appeared on her face (6), claiming that since that time, the attitudes of other people have changed to some extent, whereas hers have remained the same, namely as easygoing as before. The stories 'On the train' (2), 'At the butcher's' (2), and 'Chimney sweep' (6), present three events of Maria's life after she got married. In each of these there are human characters. Maria and the Other (Polish society) represented by individual people – the butcher, the clippie, the chimney sweep, and two inanimate characters – the body height and a wedding ring. In the abstract of the narrative (Labov and Waletzky 1967), Maria says that she "found herself in such situations," with which she places herself at the reciprocity end of the agency-reciprocity continuum (Bamberg 2011), and such positioning by the Other recurs in other stories. On the train, the clippie talks with Maria's husband, telling him that he should buy an ice-cream for his child. Both the label – child and the activity – buying an ice-cream and talking to an adult – classify Maria as a member of the category children (cf. MCD Sacks 1972). When they get off the train, Maria self-positions along the lines drawn by the clippie – she requests the ice-cream immediately – a behavior characteristic of a child rather than an adult. Despite the fact that all human rights laws apply equally to children and adults, the position of the child in society in terms of power is inferior. The mere fact that children should be valued, cared for, and protected in society, positions them as the recipients of social action rather than social actors in their own right. By way of analogy, because of her short stature, a woman with TS is treated as a child and thus she enjoys the same human rights as everybody else, but she is afforded a lower status. For example, on the train, the relationship between Maria and her husband is construed as a father-daughter, while in other contexts, it is an adult-child relationship – an underprivileged position where Maria is constantly supervised and controlled by the Other. Moreover, the social power of the other inanimate character – the wedding ring – that was expected to change Maria's social category membership is weaker than the categorizing power of short stature. In 'At the butcher's,' Maria's attempt to align with the group of women with the aid of the wedding ring fails in the context of her short stature whose social categorization power proves much stronger. At this point, Maria assumes agency in claiming membership in the category of children, which is evidenced in taking off the wedding ring. She surrenders to being socially identified as the child and different to the woman.

A change in the category membership ensues when another inanimate character and a biological actor – wrinkles – is introduced (7). Seeing them in semiotic terms as markers of old age, Maria claims that with their appearance on her face a new identity of a mature woman developed since "how we are perceived, who we socialize with, how we are judged and ordered socially is crucially determined by our age, or our location within an age categorization" (Twigg 2009, p. 97). Wrinkles, being an embodiment of old age, can be conceptualized and evaluated

differently. When looked upon from the point of view of knowledge and experience an individual acquired throughout their lifetime, they can be a metonym of wisdom; from the point of view of physical capacity and body appearance, however, they are a symbol of weakness and ugliness. Contrary to master narratives of old age in which people make efforts to mask and repress its signs made in the body domain, Maria considers wrinkles to be a sign of maturity that attests to the existence and presence of the female in her identity. Unlike the wedding ring, wrinkles being a part of “deep biological background” (Searle 1994) are a powerful actor in social contexts that in an uncontrolled manner communicates unambiguous messages about the age of a person and their social position. Wrinkles become a protagonist that conquers the social power of TS that Maria has never acknowledged. Regardless of where the social power is located, Maria is always positioned at the reciprocity end of the continuum. Earlier in life, the main symptom of TS, short stature, was agentive in her inferior social positioning, and now wrinkles took over that role. The positioning afforded by wrinkles situates Maria as socially equal to other members of the community.

The moment wrinkles appeared on Maria’s face is pivotal for how she makes claims about her group membership, i.e., she starts overtly labeling herself as a woman, and other characters also name her ‘madame’ (9). Nonetheless, this group membership is not central since it is qualified with adjectives ‘little’ or ‘short’ that pronounce the main attribute of a TS body – short stature. Fuzziness of the boundary of identity category is further illustrated in the story where a son of Maria’s friend categorizes her as a non-central member of the class ‘child’ by modifying it with the attribute ‘big’ (10). It is not clear why the boy called Maria ‘big kid,’ yet the story has been delivered to illustrate false identifications made on the basis of the body height, while the earlier mention of wrinkles may suggest that they were taken to indicate the older age.

Finally, evaluations of the events recounted and justifications for the stories delivered in interaction are argued to be revealing for identity navigation (Labov and Waletzky 1968). In the interview, Maria overtly evaluates the events as ‘funny situations’ (12), and further describes her own stance in these situations as light-hearted but not unconcerned (14). She considers them to be attestation to her true physical condition, and therefore acknowledges the rightfulness of the Other making them. Furthermore, she makes alignments with this categorization claiming it to be inscribed in biology.

Rozalia

Rozalia (26) was diagnosed with TS when she was ten. Immediately after the diagnosis, she was provided with GH therapy that lasted for two years and she grew up to 160 cm. One year after the diagnosis of TS, she was also diagnosed with Addison’s disease, which in Rozalia’s opinion, is a far more serious health problem than TS. In her struggle with her health condition, she received great

support from her parents and her younger sister. On the other hand, she felt excluded from the groups of age mates at school. At the time of the interview, Rozalia was a university graduate with a degree in Italian studies. She lived with her parents and worked for an international company.

1.	Interviewer: Do you think it's better that other people do not know that you have TS?
2.	Rozalia: Yes, I think so. In elementary school, kids teased me just because I wore glasses, so I think if they knew that I had a genetic disease, it would be worse, they would stigmatize me even more.
3.	Interviewer: Do you remember any situations where you were stigmatized?
4.	Rozalia: Well, in high school I was not called names, but I was pushed to the margins of the class. For example, once my classmate and her boyfriend invited me to their eighteenth birthday party, and other classmates asked why they did that. They thought I would not come anyway. But I showed up there, and their excuses for not inviting me to parties failed.
5.	Interviewer: Did they invite you to other parties?
6.	Rozalia: No, never.
7.	[Some lines skipped]
8.	Interviewer: And what does it look like at work? Do people know you have TS?
9.	Rozalia: They know that I am disabled because I work seven hours, which is one hour less, as people who have a moderate or severe degree of disability are entitled to a seven-hour working day, and so I was employed, so these people know that I am sick, I work shorter hours. But they know that I have Addison's disease, because I told them so that they would know that when I for example faint, they need to call the ambulance so that I get hydrocortisone right away. They do not know that I have TS, though.
10.	Interviewer: And have you ever revealed that you have TS to either strangers or friends?
11.	Rozalia: Well, yes, once.
12.	Interviewer: Can you tell me about that situation?
13.	Rozalia: It happened during the preparations for the World Youth Days with Pope Francis. We, me and my sister, went to a meeting, one in a series, where the commandments were discussed. On that day the commandment 'do not kill' was reflected upon, and then a priest spoke about abortion, and after that, after the sermon, although it was not a sermon, because it was not during the mass, but after preaching, anybody could make a comment and I spoke and said that I have something like this and that I do not understand why disabled or ill people are killed, because they can function very well in society (...) and they are productive
14.	Interviewer: And how did that group react to that coming-out back then? Were they people you knew or strangers?

15.	Rozalia: My sister was with me, but most people were strangers. Some people came up to me and hugged me.
16.	Interviewer: Was it pleasant for you? Or did you rather think it was so out of pity?
17.	Rozalia: Nice. It surprised my sister because earlier I told her that I was going to reveal that and she was so afraid of how people would react, but when these people approached me and hugged me, she was so pleasantly surprised.
18.	Interviewer: Was it just that they hugged you in such a gesture of solidarity or did they say it was great that you came out?
19.	Rozalia: They said it was great that I did something like that.

The interview with Rozalia includes a series of horizontally related stories about her relationship with her peers, which can be given an all-encompassing title “My secret life with TS.” This overarching narrative encapsulates several parallel stories about events that happened in different periods of Rozalia’s life (primary school, high school, workplace) that frame Rozalia’s perspective on her own genetic condition and the social relationships she developed with her peers.

In each story, Rozalia is a single-person protagonist who is portrayed against a group antagonist (peers). In the stories about school years, Rozalia is the character who seems to be positioned by peers as different and excluded from the group. Speaking about herself, she uses passive constructions while the group character seems to play the role of ‘the doer,’ since their activities are expressed in the active voice. Each story develops around an event in which Rozalia experienced social harassment. The reason why she was harassed and isolated at school is neither clearly explained nor overtly attributed to her TS condition that she did not reveal to her peers (2).

Given that TS is not articulated on Rozalia’s body, it can be argued that she felt different and that she made conscious efforts not to verbally reveal her condition in order to protect her status as a ‘normal’ schoolgirl (2, 4). Lucas and Phelan (2012) note that a label of illness reduces an individual’s interpersonal power, and lowers the status of an individual in the group. Concealing TS, Rozalia aimed to protect her self-worth but this, contrary to her intentions, led to self-stigmatization and internalization of negative social perceptions of TS that subsequently were projected as an actual behavior of her peers. In one of the stories (4), she voices her distress about not being invited to parties, but in the same story, she also quotes her classmates who say that inviting her to the party is pointless because she would never come. This suggests that the schoolmates must have had prior experience with Rozalia neglecting their invitations. On the other hand, Rozalia evaluates not-inviting her to class parties as a sign of social marginalization, and calls the peers’ justification of that an excuse for isolating her. Her subsequent conduct (going

to the party) can be understood as challenging unequal performance expectations (Berger et al. 1980), and an unsuccessful attempt to change her positioning, a result of which is reproduction of her original status of a 'different' person in the class. Hence, a claim can be made that TS is an actor with real agentive power, and Rozalia's agency consists of keeping TS secret.

Another confirmation of such positioning is illustrated with Rozalia's behavior at work (8). Rozalia shares information about her health with her coworkers partially, listing only Addison's disease, but refrains from mentioning TS. One can only speculate about the underlying reasons for her partial disclosure. First of all, in cases of abrupt lowering of cortisol in blood, Addison's disease can be life-threatening while TS is not. Therefore, Rozalia revealed her condition with Addison's disease anticipating possible life-threatening incidents, and hid TS which is not a life-threatening condition. Another reason why Rozalia decided to conceal TS could be its main symptom - degenerated ovaries which caused infertility. Awareness of future involuntary childlessness has a significant negative social impact on the lives of the infertile woman and her family members. In the 'Coming out' story, both characters, Rozalia and her younger sister, fear the stigma of infertility (16), which indicates that TS is a factual "undercover" agent in Rozalia's life; the actor that holds power over Rozalia, and the actor that stigmatizes and isolates.

A change in positioning, i.e., movement toward the agency end of the agency-recipient continuum, can be observed in the story about Rozalia's coming out of the closet (12), when she reveals her genetic condition to a crowd of strangers gathered at a religious meeting. The disclosure becomes a turning point of Rozalia's identity construction. She feels part of the group, and other people are close to her (they approach and hug her) (16). Recipient and difference inscribed in Rozalia's social roles diminish, and she agentively navigates her social positioning. She makes an independent decision to disclose and voice her critical views about dominant discourses on disabilities, Turner syndrome in particular. Nonetheless, she would not become the same as others if others did not agree to that positioning, they approached Rozalia, hugged her, she was brave (16, 18). Her coming-out was performed in a context of religious congregation which promote strong pro-life views and 'love of neighbor' (12), and Rozalia anticipates social approval and support. In other settings (workplace), however, TS remains secret, and one cannot say that in solving the agency-recipient dilemma, Rozalia self-positions with agency. Rather, her positioning is a dialectic outcome of personal agency and the world-to-person fit (Bamberg 2011).

Conclusion

This paper has examined the stories by three women with TS of their experience with their condition. Its aim has been to show how, through their narratives, the women integrate the experience of living with TS into their life story and make the everyday details of coping with TS part of their sense of the kind of person they believe themselves to be.

The focus of the analysis falls on the way the characters of the stories (protagonists and antagonists) are positioned. Since the stories are first-person narratives, and the protagonists can be identified with the storytellers, the analysis is argued to disclose how the tellers solve the three identity dilemmas (agency-recipientcy, sameness-difference, and continuity-change).

Each story reveals the fact that a sense of difference from the Other in society is not only constructed by the women with TS but it is also observable in the attitude that others express toward them. The women with TS are positioned as different, mainly on the basis of one physical abnormality articulated on their body, namely short stature. They themselves self-position as different, comparing their own overt characteristics (short stature) and covert physicality (infertility) as well as behavior with that of their peers. From the beginning of their lives, the sameness-difference dilemma rests on the difference end of the continuum, and moves toward the sameness end upon the completion of GH therapy, as it produces the physicality that meets the social norm. Yet, because infertility is incurable in TS, it seems to never reach the other extreme (total sameness). In the case of women who did not receive GH therapy (Maria) and whose physicality discloses their condition, that positioning does not change at all, i.e., the TS women self-position and are positioned as different.

Resolution of the continuity-change dilemma seems to be determined by GH supplementation. Upon the completion of the GH therapy, its regime ceases, and the girls reach average height in society. This leads to the normative indistinctness of their female body, which enables them to claim a more centrally located membership in the gender group in which they were only peripheral members before. Their central membership is illegitimate as their biological constitution (gonadal degeneration) leads to involuntary childlessness, and childbearing is considered central to social construction of womanhood and femininity by Polish women with TS. Hence, the identity of non-central members in the 'woman' category continues throughout life.

The agency-recipientcy dilemma is more complex to navigate, yet in most cases its resolution parallels the continuity-change dilemma. Early in life, the girls' positioning falls closer to the recipientcy end of the continuum, since they are underage and their legal guardians must consent to the treatment and medicalization. In addition, the girls are uninformed about the therapy because medical staff discuss the issue with their guardians rather than the girls. In early adulthood, when, as a result of HRT, the body of the woman with TS attains normative indistinctness, she can make her own legally independent decisions, which usually consist of the continuation of hormonal therapy. In most cases, the decision to continue this is quasi-independent, as the women strive to meet the norm and beauty standards imposed by society. Therefore, their agency contributes to their decision on either becoming socially 'invisible' (more frequent in the Polish community) or remaining, to some extent, physically different from the norm established by the society.

The findings from this research by no means can be taken as representative of the whole community of females with TS. First, the research was conducted with a relatively small population that includes adult females born, raised, and living in Poland. Hence any attempts to generalize the conclusions to embrace women with TS living in different ethnic and cultural environments are virtually unattainable given identity is a social construct. What is more, even in the present era of globalization, Polish society remains fairly conservative, especially the older generation, as far as gendered roles and identities are concerned. As a result, a cultural stereotype of femininity is embodied with a neat decent woman whose primary social roles are to bear children and nurture her family. Furthermore, the study included adult women whose identities have already been developed, and who delivered stories of their real self based on the prior experiences they lived through. If younger, adolescent females were interviewed, whose identity development has not been completed, different portrayals might be realized. What is more, women with TS living in rural areas were not included in the study since they did not agree to being interviewed about their condition.

Finally, the distribution of topics varied from one interview to another. Younger women who were students did not devote much space to the issues of fertility and reproduction, yet they expressed concerns about their physical appearance and 'feminine look,' while the pattern of topic prominence in the interviews with the older women was reversed.

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