A paradigm shift to neurodiversity model in the representations of autism spectrum disorder: in what ways do autistic Japanese YouTubers challenge the medical view of autism?

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Abstract

The medical model defines autism as disorder and disability which includes deficits in social communication, repetitive behaviour, abnormalities in sensory processing and cognition. The definition implies a need for a cure and alleviating autistic traits. However, the medical model has been challenged by the neurodiversity model, which understands autism as a neurological difference rather than a disorder. The neurodiversity movement started in English speaking autistic online communities and aims to embrace the differences, reduce stigma and create autistic culture.

This thesis aims to find out if, and in what ways, do Japanese autistic Youtubers challenge the medical model. There is a lack of studies on Japanese autistic communities, neurodiversity movement and first-person views. Ten YouTube videos made on autism by Japanese autistic or other neurodivergent people were selected for qualitative narrative analysis.

While most YouTubers presented a conception similar to the medical model, they also subtly challenged it by presenting themselves as an authority on autism, showing the positive sides of autism, critiquing universal applicability of stereotypes, using labels for autism created in autistic communities and suggesting changes in the socio-cultural environment as a way to mitigate challenges. While there were no direct references to the neurodiversity movement, there has been an increase in online content made by autistic people, which enables changes in discourse in future.

Keywords: medical humanities, disability studies, autism, neurodiversity, online communities

1. Introduction

Autism, in medical discourse, is defined as a mental disorder that includes deficits in social interaction and communication, repetitive behaviour, atypical sensory processing and difficulties in regulating emotions. However, in the past two decades, autism has been growingly reconceptualised as a form of neurological difference rather than a disorder. This idea started online in English speaking autistic communities and is commonly known as the neurodiversity model. The shift from a *disorder* to *difference* is relevant: it changes how medical institutions, autism organisations, public policy and society should treat autism (Baker 2011). Defining autism as a disorder implies a need to mitigate or cure the condition itself; defining it as a difference does not. While accommodations and support might be required for some, the narrative of difference also allows celebration-oriented agendas and creation of autistic culture (ibid.).

The neurodiversity movement has similarities to other disability movements based on the social model of disability, and they share the sentiment of 'nothing about us without us' (ASAN, n.d.). It is a neurology based civil rights movement that considers the stigmatization of autism and the focus on its cure as social oppression. It also shifts advocacy into the area of identity politics, by considering autism as a crucial part of one's identity (Singer 1999, Runswick-Cole 2014). Medical and state institutions should focus on supporting autistic people in ways that autistic people themselves see most important, rather than changing or 'curing' them how the rest of the society desires. For many proponents of the neurodiversity model, society and institutions have neglected to offer adaptations for those whose brains are different from the majority (Baker 2011).

The difference between the medical model and the neurodiversity model shows that while medical observations of autistic behaviour and cognition might be correct, the language how these are presented is not a neutral reflection of the empirical world (Prentice 2012, 163). An interpretative approach that recognizes medical knowledge as socially constructed is important. Oliver (1992) argues that disability studies have been dominated by positivist research approaches that involve disabled people only as research objects. Not involving disabled people in the research designing maintains their subordinate place in society. Autism studies tend to exclude the autistic people’s experiences and instead focus on the experiences of parents (DePape and Lindsay 2016). However, the neurodiversity model frames autistic people as legitimate and necessary sources of knowledge.

Internet improved communication and allowed community building for autistic people in new, ground-breaking ways (Blume 1997, Singer 1999, Bagatell 2010, Watabe and Suzuki 2015). With the spread of internet and English competency around the world, the ideas of the neurodiversity model have had an opportunity to spread to autistic communities in other societies. Japanese disability movements in earlier decades were inspired by movements born in the US (Hayashi and Okuhira, 2001; Stibbe 2004, 22). Unfortunately, research on the neurodiversity model in other countries or languages is lacking. This thesis aims to fill that gap by looking at how Japanese speaking autistic people understand their condition. The research question is the following: in which ways do the autistic Japanese people challenge the medical model by reconceptualizing autism? Do they recognize the ideas of the neurodiversity model in their understanding of autism?

The research includes a qualitative narrative analysis on a sample of YouTube videos on autism by Japanese speaking autistic people. Analysing YouTube videos enables cheaply and efficiently to access first-person experiences of Japanese autistic people. Due to YouTube's popularity, it is a powerful platform for activism and sharing information. There have been a few studies on YouTube videos that focus on autism (Basch et al. 2017, Kollia et al. 2017, Bellon et al. 2019 and Azer et al. 2018). However, only one study by Angulo-Jiménez and DeThorne (2019) discusses the prevalence of the neurodiversity model.

The structure of this thesis is the following: first, the literature review discusses how autism has been defined in the medical discourse, and how it has been increasingly challenged by the neurodiversity movement. Last in the literature review is research on autism in Japan, where significant gaps are found, especially from the first-person point of view. The methodology chapter discusses narrative analysis in disability studies and how it is done in this thesis. Results section discusses the main findings. While neurodiversity movement is not noticeable in the narratives, Japanese autistic people in Japan are increasingly voicing their own experiences and subtly challenging the essentialist view of autism. The conclusion will summarize the findings and discuss their importance and opportunities for future research.

2. Literature review

2.1. Defining autism

2.1.1. Scientific classifications of autism

Autism Spectrum Disorder (later ASD or autism) is medically defined as a mental disability that includes deficits in social interaction and communication, difficulties in sensory processing and regulating emotions as well as repetitive behaviour. However, all psychiatric conditions are, to some degree, social constructions. Grinker et al. (2011, 115) argue that changes in scientific classification have less to do with advancements in science than with changes in social and historical context, such as public attitudes. The scientific classification of autism has undergone several changes since it was first defined by Kanner in 1943, which reflect changing conceptions of autism within the medical, scientific community and the general public.

Kanner and Eisenberg created a strict criterion for 'early infantile autism' in 1956 (Wing 2005, 198). However, Kanner's autism was what nowadays is understood as 'severe' autism, with non-verbal tendencies and lower than average IQ. Lorna Wing, another pioneer in autism research, proposed another diagnostic label in 1981 for a condition described by Hans Asperger in 1944: 'Asperger's syndrome' (Wing 2005). It was similar to Kanner's, however with at least average IQ and no language delay. Even though she was also the first to define autism as a spectrum disorder which included both Kanner and Asperger's syndromes, this separate label was an attempt to avoid the negative stigma of 'autism' (Wing 2005, 197; Silberman 2015, 381). Wing (2005, 201) claims 'Asperger's syndrome' increased interest in autism, understanding of the difficulties and appreciation for the special skills of some autistic people.

Most countries use one of these two diagnostic manuals: The 5th edition of The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) by American Psychiatric Association from 2013, or the 10th edition of International Statistical Classification of Diseases and Related Health Problems (ICD-10) by the World Health Organization from 1990. Both manuals used to recognize subtypes such as Asperger's syndrome, but the DSM-5 collapsed them into a single term, *Autism Spectrum Disorder* (American Psychiatric Association 2013; Grinker and Cho 2013, 50; Watanabe 2020, 113). WHO also plans to collapse Asperger's syndrome and other subtypes into ASD in their upcoming 11th edition (WHO 2020).

According to Kuroki et al. (2016, 371), the government of Japan uses ICD-10 criteria, although medical research institutions prefer DSM-5. This means that Japan still diagnoses people with 'Asperger's syndrome'. However, Watanabe (2020, 117) says that the use of the word in Japanese publications has been in decrease since the DSM update. In English speaking autism communities, the use of 'Asperger's syndrome' also appears to be in decline[1]. There are two reasons: first, removing the label from diagnostic criteria, and second, new evidence on how Hans Asperger was complicit with the Nazi regime and a proponent of eugenics (Sheffer 2018; Czech 2018). These examples show that both scientific advancement and social and historical context influence the appearance and disappearance of scientific classifications.

2.1.2. Difficulties in defining autism

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[1] Author's observation from English speaking communities, especially on YouTube and Facebook.

> *"The story of autism and Asperger's syndrome attests to the truth of three wise sayings. There is nothing new under the sun. Nothing exists until it has a name. Nature never draws a line without smudging it. "*
>
> Wing, 2005:202

As history shows, defining autism is challenging. ASD is a product of "the interplay between biological, psychological, and cultural phenomena (Grinker et al. 2011, 112)." There are cultural differences in how certain autistic traits are understood in different societies and cultures (Carruthers et al. 2018). Grinker and Cho (2013, 47) say that conceptions of autism are created and recreated by the medical establishment, parents and teachers. Furthermore, it is increasingly recreated by autistic people as well.

Three difficulties in defining autism have been identified. First is the question which traits and in which intensity constitute autism. Some research suggests autism is a spectrum not only with its subcategories but also with normality (Wakabayashi et al. 2006). Verhoeff (2012, 417) argues that autism does not have a 'true' core that makes it a distinct natural entity. Thus, there is no clear line one must cross to be counted as autistic. Both creating and interpreting the diagnostic criteria is challenging and can lead to different results in who gets a diagnosis and who does not.

Second, the causes of autism are unknown. Autism is considered highly hereditary, but scientists have failed to find genes that would explain more than a fraction of autistic traits. Studies have been done on environmental factors such as diet, gut fauna and vaccinations, but the evidence is usually non-conclusive. For example, Gardener et. al (2009) made a meta-analysis on over 50 prenatal risk factors but could not find sufficient evidence for any. Tseng et. al's (2019) meta-analysis suggests that autistic children were less often breast-fed. Modabbernia et. al’s (2017) meta-analysis suggests some environmental factors, such as high parental age, are linked to autism, but factors such as vaccination or maternal smoking, are not. However, since autism and autistic traits appear to be hereditary, having children late in life or not breastfeeding might correlate with one’s autistic tendencies. Unsurprisingly, no cure for autism has been found either.

Third, autism is a disorder that is highly influenced by what is considered ‘normative’. Link and Phelan (2012, 311) claim stigma is a result of “perception that somebody is undesirably different from a societal norm”. Some autistic traits, such as lack of eye contact or monotone voice, are non-normative but do not cause direct harm to anyone (Armstrong, 2010). Tisoncik (2020, 70) criticises institutions for trying to wipe autistic people from their identity, and that their “every ‘treatment’ and ‘care’ is an act of violence against who we are.” There are ethical issues in homogenizing society by assimilating autistics without their consent. One needs to be critical about which aspects of autism cause real harm and need medical intervention, and which are harmless differences in behaviour and cognitive ability.

For this research, a person is considered autistic if they have autism or Asperger’s syndrome diagnosis, or they are self-diagnosed. This is because there might be barriers to diagnosis, such as money, insurance policies or unwillingness to diagnose adults. There is also a gender bias in autism research which makes it is harder for women to get diagnosed (Rudy 2010). For this research, if one identifies with autism, suspects to have autism or relates to autistic traits and discusses them from their personal point of view, they will also be counted to the sample.

2.2. Paradigm shift: the medical model vs. the neurodiversity model

In English speaking discourse, there are two main ways how autism is conceptualised: the *medical model* and the *neurodiversity model*. The medical model is an essential understanding of autism that sees the problems arising from the disabled body, whereas the neurodiversity model has a constructivist understanding and sees the problems arising from the interplay between the person and their socio-cultural environment. The medical model focuses on curing the autistic individual, and the neurodiversity model focuses on adapting the environment to fit the needs of autistic individuals. The medical model has a long history in the medical institutes and society, whereas neurodiversity is a newer, autistic-led movement that started as a critique of the medical model. The names for these two models and their descriptions arise from disability scholars and activist, and health care professionals rarely use the terms to describe their stance (Baker 2011, 8).

2.2.1. The medical model

The medical model is typically the way how advocacy organisations and medical institutes conceptualise autism. It focuses on biology and the impaired body as the source of disability. This means that the medical establishment and the biggest autism organisations devote most of their funding on curing autistic traits instead of providing services for autistic people (Kapp 2020, 5; Evans 2020, 128; Silberman 2015, 16). These priorities of medical institutions and organisations are heavily criticised by some autistic people. For example, developing prenatal screening to detect autism is criticized as eugenics (Evans 2020, 128). Most organisations for disabled are typically being controlled by non-disabled parents (Sullivan 2013, 3). This is also a common critique towards Autism Speaks, the biggest autism organisation in the world, which only has one autistic member on their board of directors (Autism Speaks 2020c).

The medical model offers a lens of analysis which typically considers autistic voices as unable to speak for themselves. Baron-Cohen et al. (1985) were the first ones to suggest that autistic children lack the theory of mind, the capability for empathy, understanding others and predicting others' behaviour. Yergeau (2018, 22) criticizes the constant scrutiny on autistic people's abilities: the more signs of lack of theory of mind you search, the more you find. This has led to disregarding autistic people as an authority on autism. Instead of seeing the actions of autistic people as stories of individuals, they are considered as symptoms (Yergeau 2018, 2). The prevalence of the medical model in media leads to portraying autism as something that 'affects' people and creates stories of tragedy (Murray 2008, 2). If an autistic child refuses a hug, the focus is on neurological explanations for such behaviour rather than understanding the child's perspective (ibid., 3).

2.2.2. The neurodiversity model

Autism is growingly understood as a form of 'neurodiversity', a neurological difference rather than deficit (Blume 1997; Silberman 2015; Singer 1999; Armstrong 2010). Neurodiversity movement started as autistic people's response to the medical model that regularly dehumanizes and dismisses autistic voices. Neurodiversity includes other neurological conditions besides ASD such as ADHD and dyslexia, but also the "normalcy" of human neurology (Armstrong 2010). Those with such conditions are called 'neurodivergent', and those without are called 'neurotypical.' Neurodiversity model adopts the spectrum concept to autism, similar to the DSM-5 diagnostic criteria.

Judy Singer is credited as the first person to use the term ‘neurodiversity’ in 1998 on a mailing list for autistic people (Kapp 2020, 2). The term was more widely spread the next year in her article ‘Why Can’t You Be Normal for Once in Your Life?’. In this article, she likens neurodiversity to a political identity group similar to class, gender, sexuality or race (Singer, 1999). This shifted autism advocacy into identity politics. Neurodiversity movement aims to promote rights, prevent discrimination and organise neurodivergent people as an advocacy group (Runswick-Cole 2014, 1120). It empowers autistic people to determine what meaningful life means for themselves (Bagatell 2010, 50). The neurodiversity model endorses neurological differences as valuable, which lessens the stigma.

The neurodiversity model recognises that the difficulties of autistic people do not stem from their neurology alone. Baker (2011, 7) discusses a continuum between constructivist and essentialist understandings of autism: neurodiversity falls on the constructionist side of the continuum, whereas the medical model is on the essentialist side. The more essentialist understanding one has, the more they see it as the responsibility of the individual to manage their difficulties. However, the constructivist conception recognizes the role of the society in helping, but also in creating the difficulties. Shakespeare (2006, quoted in Stevens 2013, 10) defines ‘disability’ as a relationship between intrinsic and extrinsic factors. Indeed, environmental factors such as early diagnosis and support are more associated with a better quality of life than IQ or severity of autism (Kamio et al. 2012, 16). The neurodiversity model suggests that autism as a ‘disability’ is socially constructed and difficulties can best be mitigated by changes in the socio-cultural environment (Bagatell 2010, 38).

Nonetheless, the neurodiversity model does not come without criticism. There has been an increase in diagnoses (Winerman, 2018). This is often said to be caused by an increase in the ‘milder’ forms of autism[2], who often do not consider themselves disabled (Kapp 2020, 4). On the other hand, some can experience autism and its comorbid conditions as very disabling. If the most independent autistic people speak for the whole community, it might get harder for those who need support to get it. The parents of severely autistic people are afraid that the rise of the neurodiversity model leads to ignoring their pain. However, even if the whole spectrum did not participate in public discourse or activism, the neurodiversity movement asks for rights and awareness for the whole spectrum (Kapp 2020, 5). Nonetheless, as interest groups usually emphasize the negative aspects of autism for fundraising purposes, a positive image of autism makes fundraising harder (Armstrong, 2010). Runswick-Cole (2014, 1125) argues that claiming autism is not an intrinsic disability might imply autistic people could no longer be a ‘state of exception’ and receive disability benefits.

2.3. Online communities

The link between autism and online platforms is still as strong as when the neurodiversity movement first started in English speaking online communities (Kapp 2020, 2). Autistic communities would be few if it was not for the internet. Bagatell (2010, 33) names three

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[2] Many autistic people do not support function-labels such as ‘mild autism’, ‘high-functioning autism’, or even ‘Asperger’s syndrome’, since it is almost synonymous for high-functioning autism. These labels are typically rejected in the neurodiversity model because they define the experience of autism from outside rather than inside (Sequenzia 2012 and Burns 2019). However, these terms can still be found in some official diagnostic criteria.

factors that contributed to the birth of autistic online communities: widening of the autism spectrum, strengthening of the self-advocacy movement and the explosion of technology.

Many disability groups have benefited from technology, but this might have been even more transformative for autistic people. It not only connects autistic people but offers more suitable communication methods. If autism is defined as deficits in verbal communication and social relationships, the internet has created ways to bypass the difficulties in face-to-face communication. Many autistic people consider communication online as significantly easier (Watabe and Suzuki 2015, 12). Blume (1997), another early proponent of the neurodiversity movement, compares the internet for autistic people to what Braille is for blind people.

These autistic communities allow autistic people to find their voice and create new narratives of what it means to be autistic. Autistic people have historically been spoken for by others, but information technologies allow autistic people to speak for themselves (Blume 1997). It also enables autistic people to gain a deeper understanding of their condition, build identities, receive peer support, create autistic culture and strengthen the self-advocacy movement (Brownlow and Odell 2006, Runswick-Cole 2014, 1122). For example, in the UK, people with Asperger's syndrome formed groups online that would spark discussions on how to legitimately govern autism organisations. Some would suggest quotas for autistic board members for the National Autistic Society or would run for themselves (Wing 2005, 200). However, currently in 2020, only one board member claims to be autistic (National Autism Society 2020).

The Internet as a platform also keeps evolving. The first communities were on mailing lists and forums but 20 years later, the communities are on platforms such as Facebook, Instagram and YouTube. For example, Facebook has large autism-focused groups for different purposes: some for peer support, some for parents, some for women, and some for memes. Unfortunately, research on autistic online communities or start of the neurodiversity movement in non-English speaking context could not be found. No research on what the communities are like in Japan, and how the narratives and ideas are different from the rest of society could be found.

2.3.1. Autism communities on YouTube

YouTube is an American video-sharing platform founded in 2005. It has more than 2 billion monthly users who watch more than a billion hours of content every day (YouTube 2020). In 2020 (during the COVID-19 pandemic), YouTube has 15% of all consumer broadband internet traffic, which is more than any other website (Cullen/Sandvine 2020). In 2019, the share was 35% of all downstream traffic on mobile devices (Cullen/Sandvine 2019). These statistics show how revolutionizing platform YouTube is for spreading information.

There are a few studies on YouTube videos focusing on autism, but many focus on the experiences of parents. Bellon-Harn et al. (2019) studied the understandability of YouTube videos aimed at families with young autistic children. They say that videos made by professionals are “superior in terms of understandability (2019:263).” However, this is an example of a study where the medical model is taken as granted. To identify important topics related to autism, the researchers used controversial organisations such as Autism Speaks as their source. They used keywords related to the medical model to gather their sample, such as “autism therapy,” “causes of autism,” and “treatment of autism.” Autistic voices are underrepresented in their sample, as autistic people are less likely to promote treatment or therapy. Azer et al. (2018) ask whether there are educationally useful videos showing parents of autistic children sharing their experiences. Similar to Bellon-Harn et al. (2019), the focus is on the experiences of parents rather than autistic people. The research discusses anxieties and worries, but not those of the autistic person.

In a study by Kollia et al., (2017) the content of 100 most-watched YouTube videos on autism is analysed. 99% of the videos were uploaded by non-professionals, but all 43 ‘personal videos’ were made by parents of autistic people. Kollia et al. do not mention any videos from a point of view of an autistic person. In November 2020, a quick YouTube search of most-watched videos on autism shows multiple videos from an autistic point of view. This indicates that the presence of autistic voices in YouTube has been growing since 2017. Many channels hosted by autistic people have thousands of followers, most notably ‘The Aspie World’ with more than 136 thousand subscribers[3]. Kollia et al.’s study is thus already outdated. Also, they only discuss themes connected to parenting, which makes it another research that excludes autistic voices. The study focuses on risk factors, treatment, and describes autism a ‘health concern’, showing the researchers are the most familiar with the medical model.

Spreading misinformation on autism is common especially in anti-vaccination videos. Basch et al. (2016) find that almost half of the 87 popular videos on vaccination discuss risks of autism. Two-thirds of these videos have an anti-vaccination stance showing that YouTube spreads disinformation that fosters negative views on autism.

The only study that discusses neurodiversity and the autistic point of view in YouTube videos is done by Angulo-Jiménez and DeThorne in 2019. Their study on English speaking

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[3] Recorded in September 2020

autistic YouTubers shows that 77%, present a view of autism that is a mix of medical and neurodiversity models. 95% of the YouTubers use language that is associated with the medical model of autism (deficit, defect etc.), while only 62% of the YouTubers use language that is associated with the neurodiversity model (narrative of difference) (Angulo-Jiménez and DeThorne 2019:578). However, the researchers have a narrow view of the neurodiversity model, which possibly explains why none of the YouTubers presented a view solely based on the neurodiversity model. For example, words such as ‘obsession’ are used as an indication for the medical model due to the negative connotation (2019, 582). However, it is also possible to reappropriate vocabulary and turn them into something positive. When one talks about their ‘obsessions’, they might use it as a positive term synonymous to ‘passion.’

In addition, the criteria of ‘identity-first language’, is difficult in practice. Those diagnosed specifically with ‘autism’ can easily call themselves ‘autistic person’ instead of ‘person with autism’. However, it is difficult to use diagnoses such as ‘Asperger’s syndrome’ as an adjective. It is possible to call oneself ‘aspie’, but this is slang rather than formal language. Therefore, if you want to abide by the official (albeit possibly outdated) diagnosis, it is most convenient to call one ‘a person with Asperger’s syndrome’. This does not mean they are disagreeing with the neurodiversity model but reflects the lack of words to describe the official diagnosis as an identity. Besides, while it is now common to use ‘autistic’ as an adjective to embrace the autistic identity and empower autistic people, for some, the meaning might be the opposite. Since the 70s, some switched from saying ‘autistic person’ to ‘person with autism’ to emphasize that a person is not defined by their diagnosis (Baker, 2011:53). What some understand as empowering ‘identity-first’ language, can also be disempowering ‘diagnosis-first’ language to others.

2.4. Autism narratives in Japan

To what extent is the neurodiversity model present amongst Japanese autistic people? Similar to the West, most studies on autism in Japan focus on non-autistic voices. No existing studies on Japanese autistic communities were found. However, research on other disability movements and personal voices may provide a hint on to what extent ideas travel between English and Japanese speaking communities.

It appears that other disability rights movements in Japan have been influenced by activists in the USA (Hayashi and Okuhira, 2001; Stibbe 2004, 22). Hayashi and Okuhira (2001, 859) explain that the disability rights movements started in Japan in the 60s and the 70s together with other civil rights movements, such as feminist and anti-Vietnam war movements. They were successful in changing norms, policies and clinical services regarding disabilities (Hayashi and Okuhira 2001, 855; Angulo-Jiménez and DeThorne 2019, 569). These successes indicate that autistic people have the potential power to change the discourse. However, these movements focused on physical, and thus visible, disabilities. As many autistic people can successfully hide their difficulties, they might not feel the need for political activism. When autism is disabling, it does so invisibly.

Teruyama (2014, 141) argues that first-person narratives of adults with *hattatsu shougai* (a common term in Japanese that includes ASD, ADHD and learning disabilities, literally "developmental disability."[4]) remain personal rather than political. There is no tendency to stand up against society. This indicates that the disability rights movement has

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[4] While the connotation is more negative than that of 'neurodiversity', all people with *hattatsu shougai* are also considered neurodivergent.

not included spreading awareness for *hattatsu shougai* or autism. However, as Teruyama says, private stories about struggles in daily life can also be interpreted as enacting agency and resisting the dominant culture (ibid.).

Many studies show how ASD is a stigmatized condition in Japan. Someki et al. (2018) argue that there is more stigma towards autism amongst Japanese than American college students. There are various possible explanations. Collective values in Japan is one explanation for the hostility towards people who stand out with their behaviour yet lack visible disabilities (Ku and Bryce 2011, 501). Stevens (2013, 31) argues that there is a lack of awareness and prejudices of psychological disability. Stigma on autism discourages autistic voices from being used in public arenas, even though increased public discourse could destigmatize autism. High stigma also indicates that the narrative of neurodiversity which encourages self-advocacy has not gained support in Japan yet.

Most Japanese people lack direct contact with disabled people, which means that media has significant power in shaping conceptions (Stibbe 2004, 24). Media tends to portray all disabled people as isolated victims of circumstances without connections to other disabled people, despite many existing organisations for disabled people (ibid., 25). Furthermore, Stibbe (2004, 27) says that television dramas portray the medical model as the ideal solution for disabilities, such as being cured, stoically putting up, battling the barriers or depending on non-disabled people. The non-disabled world is constructed as the norm and something the physically disabled people must aspire to. If media spreads the ideas of the medical model for physical disabilities, it most likely does that for autism as well.

Autism is rarely represented in the media in Japan, but Bryce et al. (2014) analyse the manga series *Hikari to tomo ni* (Within the Light) with one autistic main character. As expected, the story focuses on the parent's point of view, which is typical for narratives on autism. Watanabe (2020) analyses comics on Asperger's syndrome and finds out that while the cure is not considered realistic, people with Asperger's are expected to learn more about their condition and improve. For example, one comic encouraged people with Asperger's syndrome to get rid of the attitude that 'acting' is pointless and practice smiling to make their and other people's life easier (Watanabe 2020, 128).

Currently, the support system in Japan largely relies on volunteering and goodwill and does not consider support a 'right' for the disabled people (Ku and Bryce 2011, 501). Gottlieb (2001, 981-982) argues that the Japanese system highly reflects the medical model and rejects protection of difference. However, disability organisations have been effective in curtailing some harmful vocabulary from legislation and media, even though grassroots organisations usually are not very powerful (Gottlieb 2011, 983). Nonetheless, most changes in the way disabilities are discussed are cosmetic and done to avoid public embarrassment (ibid.). Iwakuma (2005) claims that updates in the vocabulary to discuss disability are slow compared to the US. The term *shougai* ('disability', discussed more in chapter 3.2.) has been in common use for over 50 years despite its known negative connotations.

In addition, lack of awareness and even misinformation on autism and *other hattatsu shougai* is common. One study found out that busy and stressed-out teachers were considered a cause of learning disabilities (Kataoka et al. 2004, 172). Similarly, Japanese people are more likely to attribute autism to upbringing than genetics (21% vs 17% of respondents) (Koyama et al. 2009, quoted in Someki et al. 2018, 90). Although the causes of autism or learning disabilities are unknown, they are agreed to more likely be nature than nurture (Kataoka et al. 2004, 172).

Based on these sources, it is unclear how much awareness autistic people have of the neurodiversity model. None of the sources focused on specifically autistic voices or online content, which are important areas for analysis to answer the research question.

3. Methodology

3.1. Narratives in disability studies

Narrative analysis is often used to highlight the experiences of minorities or underrepresented populations, which autistic people are an example of. It has been used, for instance, to compare the experiences of autistic people to the ‘master narrative’ of science, politics and faith (Gray 2001), understand the experiences of people with psychosocial disability with Employment Services program reforms (Devine et al. 2021), or the prevalence of medical or neurodiversity model in English speaking YouTube videos made by autistic people (Angulo-Jiménez and DeThorne 2019).

Daiute (2014, 4) defines ‘narrative’ as an interplay amongst actors, whose perspectives merge and diverge in social and political processes. In this case, ‘actors’ refer to the narrator (YouTuber), other autistic people, the neurotypical people and institutions such as medical and educational. Narratives reveal power relationships between these actors in stated or implied meanings of the language. The narrative analysis identifies themes that reoccur, even if they are not the main topic of them (McAdams 2016, Page 2018). Even narrations on personal experiences might reveal issues about Japanese society. Autism as a subject matter is inherently political, as both the definition of autism and the experience of being autistic are heavily influenced by stigma and societal institutions.

Narrating is a tool to mediate self-society relationships, including connecting with people, dealing with social structures, making sense and finding ways to fit into various contexts or changing them (Daiute 2014, 3, 16). Due to the active nature of the narration, narratives do not only reflect one’s personal or social meanings but also create them. Even if society at large subscribes to the medical model narratives on autism, the YouTubers can contribute to changing this. It is unlikely that the YouTubers will directly claim which model they believe in, and thus a method that helps to understand stated as well as implied meanings of language is needed.

The narrative analysis also helps to understand identity formation, because narration is used both to perform and reflect on identities (Daiute 2014, 6). Identity is a crucial difference between the medical and neurodiversity models. The medical model conceptualizes autism as dysfunction, where the real person hides under this medical condition. Neurodiversity model conceptualizes autism as a neurological difference that is inseparable of one’s identity.

Using narrative analysis to study a group of people who have typically been judged for not being good at expressing themselves is a possible drawback. However, autistic people often feel that neurotypicals lack respect to the ways they want to communicate and over-attribute their traits to autism (Nicolaidis, et al. 2015, 828). In addition, the multimodality of a video format offers alternatives to spoken communication, such as captions.

3.2. Navigating language barriers

Angulo- Jiménez and DeThorne’s (2019) study provides useful categories for comparing the medical and the neurodiversity model. However, many of their categories do not work the same way in the Japanese language. For example, ‘identity-first’ language is possible in English (to a certain degree), but this is not a common feature of Japanese. Intuitively speaking, Japanese phrases such as *asuperugaa ga aru* (Asperger’s syndrome exists) or *asuperugaa wo motsu* (to have Asperger’s syndrome) sound as if the Asperger’s syndrome is something a person is ‘having’ or ‘holding’ in addition to their personhood, similar as in ‘diagnosis first’ language in English. Furthermore, *asuperugaa no hito* (a person of Asperger’s syndrome) sounds more integral to the person, similar to ‘identity-first’. However, references to any conscious use of abovementioned phrases to distinguish between medical or neurodiversity model are not found.

Stevens (2013), Illes and Lou (2019) and Teruyama (2014) describe the connotations of language used in Japan to discuss disability. Some consider the Japanese term *shougai* (disability, 障害) a negative term (Gottlieb 2001, 987; Iwakuma, 2005). There are several ways how the second kanji, *gai*, can be written: 害、がい or 碍 (Stevens 2013, 48). The first is the most common, but since “害” has meanings such as injury, harm and evil, some choose to use alternative characters. In Japanese, the word *hattatsu shougai* (developmental disability) is a common umbrella term for ASD, ADHD and learning disabilities. Stevens (ibid.) claims some loan words such as *disuabiriti* (disability) are also used to avoid the negative connotation. For this research, the alternative spellings of *shougai*, nicknames that are used in autistic online communities and loan words are considered as a critique towards the medical model.

3.3. Questions

The questions were decided deductively based on the literature and by using analytic induction while reviewing the sample (Sahlstein Parcell & Baker 2017, 1071). The questions were inspired by Angulo-Jiménez and DeThorne (2019, 577). However, there was no need for strict binary categories because the analysis was qualitative. Visual information, such as body language and visuals were also analysed when relevant.

1. Language
    - What labels do the YouTubers use to describe their condition?

    - For example, do they use medical terms or casual terms such as ‘aspie’?
    - Do they convey the meaning of neurological difference or disorder?
  - If *shougai* (disability, handicap) is written with kanjis, which ones do they use?

2. Topics discussed
    - Which topics are common in these videos?
    - Are these topics showing autism in a positive or negative light?

3. Source of challenges and solutions
    - When discussing difficulties, are they mainly caused by the person with autism (essentialism/medical model), or in the interplay between the person and their surroundings (constructivism/neurodiversity model)?
        - For example, does the person name autism as the source of hardships, or do they blame the aspects of their socio-cultural environment, such as stigma or lack of awareness?
    - What is the desired course of action?
        - For example, do they promote changing the autistic person or advocate for the cure of autism, or do the solutions focus on accommodation, inclusion, and acceptance of autistic people?

4. Description of autistic traits

- Do they describe autistic traits in terms of deficit, delay, defect or excess of something?
- Do they contextualize or redefine autistic traits, or try to see positive aspects in typically negatively viewed traits?

5. Allocation of autism expertise
    - Who is the main authority on knowledge of autism?
        - Is it the autistic people themselves, or neurotypical individuals such as health professionals, scientists and family members?
    - Do they question common conceptions or stereotypes of autism?
    - Do they question medical conceptions of autism?

3.4. Sampling Method

The first step was to identify channels that were hosted by a diagnosed autistic Japanese speaking individual, or someone who identifies with autism or autistic traits. Second, the most-watched video[5] on autism was selected. However, if the most-watched video was over 20 minutes long, the second most-watched video on autism was chosen. This was done in two cases.

Following keywords and their combinations in Japanese were used to find channels with at least one video on autism:

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[5] As of 1st October 2020.

autism	自閉症	(*jiheishou*)
autism spectrum	自閉症 スペクトラム	(*jiheishou supekutoramu*)
ASD spectrum	*ASD*スペクトラム	(*ASD supekutoramu*)
Asperger's Syndrome	*アスペルガー症候群*	*(asuperugaa shoukougun)*
first-person	*当事者*	*(toujisha)*
developmental disorder	*発達障害*	*(hattatsu shougai)*
aspie	*アスピー，アスペ*	(*asupii, asupe*)
neurodiversity	ニューロダイバーシティ	(*nyuurodaibaashiti*)
'brain diversity theory'	脳多様性論	(*noutayouseiron*)
neurodiversity	神経多様性	(*shinkei tayousei*)

Most videos were made by organisations, non-autistic experts or people speaking Chinese. After finding a few videos by Japanese autistic people, the YouTube algorithm showed more in the suggested videos. Another method was to investigate which other YouTubers were recommended by the selected YouTubers. Thus the 'snowballing' method proved to be more efficient than the keyword search. In the end, the sample is 10 channels and 10 autistic/neurodivergent YouTubers.

3.5. Data Collection

The following information was gathered in addition to information related to the research questions:

- Channel: starting date, subscribers, the topic focus of the channel
- YouTuber: gender, age, diagnosis

- Chosen video: title, URL, date of uploading, number of views, length, use of visuals

Roberts (2015) discusses whether people belonging to public online communities should be considered as authors or participants, and which ethical questions should be considered. Case to case decisions are crucial as each online community is different. Through the guidance of Roberts’ article, ethical decisions regarding consent, pseudonyms and traceability of the quotes were made. All videos in the sample are public and it can be assumed that the YouTubers have taken the precaution to protect their privacy, even though the videos include private and medical information. The physical appearance, full names (unless in the username) and other information of the YouTubers are not given to prevent later recognition in case they remove their videos. During the research process, one YouTuber deleted their channel. He was excluded from the sample, as withdrawing from the public sphere can also indicate a non-consent to research. Screenshots are excluded to protect the copyrights (YouTube, 2020). For uniformity, the YouTubers will be referred to with their first name or nickname, not their channel name. Full information is in the bibliography.

4. Results and Analysis

4.1. About the sample

4.1.1. Channels

The 10 channels in the sample varied with their numbers of subscribers, overall views, start date and topic focus[6]. The highest number of subscribers (as of 1st of October 2020) was 154 000, while the lowest was only 1500. The average number of subscribers was 24 000 and median 7700, indicating that most channels were small in numbers. The overall views of the channel indicate how many people they are reaching. The highest number of overall views was almost 50 million, and the lowest 100.000. The average was 6.700.000 and median 1.500.000. The oldest channel in the sample started in 2010 and they also had the highest number of subscribers and overall views. The rest of the channels started in 2016 or later, showing that there has been an increase in YouTube content creation amongst autistic people in recent years.

Only two of the 10 channels had a significant focus on ASD, in addition to one YouTuber who had an ADHD focus and regularly posts videos on ASD. Three of the videos in the sample were 'coming out' videos, where the YouTuber disclosed for the first time on their channel that they have autism.

4.1.2. YouTubers

In the sample of 10 YouTubers, only 3 were male. This is unexpected, as the ratio of diagnosed autistic men to women is four to one (Autism Speaks, 2020a). However, female autistic people typically have fewer communication difficulties and are more able to

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[6] The numbers are rounded to the nearest two decimal places.

'camouflage' them than male autistic people (Lai et al. 2011 and Lai et al. 2016). Vlogging requires an interest in spoken communication, and while YouTubers have the freedom to talk in their own terms, for the most introverted people vlogging might not be appealing. This could explain why the ratio of men and women was the opposite compared to the general population of diagnosed autistics. Most of the YouTubers did not specify their age, but the majority seems to be in their 20s or early 30s. This age group has spent most of their life with the internet, and thus they might be the most drawn to communicating online.

Eight out of the ten YouTubers said they had autism, although three used the term 'Asperger's' instead. Whether the diagnosis was official or not, was not always obvious. Two out of the 10 YouTubers told they were diagnosed with ADHD and told to have autism tendencies. It was not clear if they consider themselves autistic but lack formal diagnosis, or only see some similarities. Nonetheless, they were included in the sample because of their personal point of view on describing the traits and the tendency in Japan to put both ADHD and ASD together as *hattatsu shougai* (developmental disability).

Table 1: YouTubers

Name	Subscribers [7]	Views on the chosen video	Upload year
Hiromi	11.000	160.000	2019
Miiko	3.800	67.000	2019
Atsurou	150.000	480.000	2020
Ayano	5.600	300.000	2017
Shiori	2.900	7.300	2018
Arufu	6.700	2.000.000	2017

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[7] Rounded to the nearest two decimals. Numbers recorded on 1st October 2020.

Katsu	37.000	1.000.000	2019
Kurumi	1.500	5.300	2020
Rei	8.700	8.600	2020
Rio	11.000	5.300	2020

4.1.3. The chosen videos

In average, the chosen videos had 400.000 views. The highest number of views was almost two million, the lowest 5000, and the median 110.000, showing vast differences. The oldest two videos were uploaded in 2017, and almost half (4) were uploaded in 2020, even though the sample was made on the first of October 2020. This shows that the use of YouTube to discuss their own experiences amongst autistic people is growing.

4.2. Research Question

4.2.1. Labels and language

This chapter analyses the labels that the YouTubers used for their condition. They can, for example, convey the meaning of a medical disorder or disability (medical model), a neutral neurological difference, or even an autistic identity and belonging to autistic communities (neurodiversity model). As we will see, most of the YouTubers used terms that lean towards the medical model, with only a couple of exceptions that indicate belonging to autistic communities.

Hattatsu shougai was a word used in 9 out of 10 videos. The term means a ‘developmental disability’, which emphasizes the negative parts of the conditions and focuses on the ‘disorder’ narrative rather than ‘difference’ narrative. *Hattatsu shougai* includes various diagnoses such as ASD, ADHD and learning disorders, similarly to the term 'neurodiversity'. However, the connotation is more negative than that of neurodiversity (as discussed in detail in chapter 2.3.2). *Hattatsu shougai* is not a medical diagnosis, but a term used by both lay-persons and psychiatrists (Teruyama 2014, 3). This is convenient since many traits overlap with other diagnoses. In this sample too, more than half of the YouTubers also had ADHD, and it might be impossible to say which traits are part of which diagnosis. Interestingly, none of the YouTubers used any alternative spellings for *shougai* (for example, 障碍 or 障がい), and instead used the mainstream version (障害) that has the meanings of injury, evil or harm. This a sign of lack of criticism towards mainstream and medical terminology.

The only YouTuber who opted not to use the term *hattatsu shougai* was Atsurou. However, Atsurou also did not use the word 'autism[8]' even once in his almost 20-minute-long video. Instead, he only discussed Asperger's syndrome and ADHD. He was diagnosed only a couple of months before filming the video, which could mean that he was not engaged in the Japanese discourse on autism. However, he was an outlier in the sample by having a substantially larger number of followers than others. Therefore, the possible reasons for the non-use of both 'autism' or 'hattatsu shougai' could be an attempt to avoid the stigma and giving negative images to his followers.

Noticeably many YouTubers described their condition as 'Asperger's syndrome', which is an outdated label in the DSM criteria and will be outdated in Japan in a couple of years when ICD-11 is published. This shows that the autistic community does not seem to have changed their conceptions on autism based on the newest diagnostic criteria or the revelations made about Hans Asperger (Sheffer, 2018; Czech, 2018). Some YouTubers, for

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[8] Japanese: "*jiheishou*"

example, Hiromi (2019, 0:31), corrected that Asperger's syndrome is now a part of ASD. Three YouTubers, Atsurou, Rei and Ayano only discussed their condition as Asperger's syndrome, not autism. This could either be due to the stigma or lack of diffusion between the English language and Japanese language discourse on autism. Wing (2005, 197) discusses how 'Asperger's syndrome' had a more positive image than 'autism', which could still be true in Japan where autism is stigmatized.

Miiko said that she has been suspected of 'mild autism[9]' (2019, 0:25). This is medically up to date, as DSM-5 defines levels of autism based on the accommodations needed (Autism Speaks, 2020b). However, this term is not common in neurodiversity narratives. Many autistic people are critical towards the function labels (for example, high/low-functioning autism) since the judgement of one's autism level is based on the view of outsiders rather than the experience of the autistic person. However, as the level of support is a relevant thing to discuss, many use these labels out of convenience.

None of the YouTubers used words clearly associated with the neurodiversity model. Arufu and Hiromi were the only ones using terminology created in some autistic communities. Hiromi's video was an introduction to the 'Aspergirls' book by Rudy Simone. Rudy herself identifies as autistic, and 'Aspergirl' is a way how girls and women with Asperger's syndrome show ingroup identity (Spectrum Suite, n.d.). Arufu (2017, 0:31) used the term *asupe* and specifically said that this was a common term online. *Asupe* sounds similar to 'Aspie' in English but is most likely a contraction of the Japanese pronunciation of 'Asperger's' rather than a term that has diffused from English speaking communities. This

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[9] Japanese: *"keido no jiheishou supekutoramu"*

proves that at least some Japanese autistic people are connected to Asperger's syndrome online communities and are influenced by them[10].

These observations show that when it comes to labels, the YouTubers did not challenge essentialist conceptions of autism. Kurumi (2020, 1:40) even accidentally called her autism a 'disease[11]'. Nonetheless, she apologized in the captions. Whether the YouTubers were aware of the alternative terms for autism is unclear. Labels originating from autistic communities were confirmed in two cases: two YouTubers used the terms *asupe* and 'Aspergirl'. They imply ingroup identity for those who have Asperger's syndrome, but not autism or neurodivergent people as a whole.

4.2.2. Topics Discussed

The most common main topic was autistic traits[12]. This was in the title of four videos (those of Hiromi, Miiko, Arufu and Katsu); one of them focused on general traits of ASD, two of them focused on the autistic way of speaking[13] and one on gender differences in traits. Kurumi's video also focused on autistic traits although from a significantly more subjective point of view. The second most common main topic was a diagnosis, which was expressed in the title of three videos (those of Atsurou, Ayano and Shiori). These videos mainly discussed feelings related to receiving a diagnosis and the reasons why they or someone else

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[10] A further look into Akira's channel showed a video on 'neurotypical syndrome', a term used by autistic people mocking non-autistic or neurotypical people (Arufu, 2017b). This term, which flips the table by humorously pathologizing non-autistics instead, gained popularity during the early 2000s through a satirical medical institute called 'Institute for the Study of the Neurologically Typical (Tisoncik, 2020:73).' While this video is not in the sample, Akira was the only YouTuber encountered who was aware of the neurotypical/neurodivergent divide that is used in English speaking autistic communities.

[11] Japanese: "*byouki*"

[12] Japanese: "*tokuchou*"

[13] Japanese: "*hanashikata*"

suspected autism and decided to get diagnosed. These two topics, traits and diagnosis, were touched upon in most videos. The remaining two videos focused on reasons for starting a YouTube channel (Rei) and finding a job as an autistic person (Rio).

Most topics were neutral and not directly showing ASD as a negative nor positive issue. For example, the characteristics of autistic speech[14]. This topic focuses on differences between autistic people and non-autistic people, which is a neutral difference rather than a disorder. Feelings related to receiving a diagnosis is also a neutral topic. The subjective feelings varied from person to person. For some in the sample, their diagnosis was a relief (Ayano 2017, 7:58), whereas for some it was a shock (Shiori 2018, 5:09). Hiromi's video on the different characteristics of autism in men and women is also a neutral topic, even though most of those characteristics are what society considers negative. Nonetheless, specifically celebratory topics, which emphasize autistic culture, strengths or achievements were not found in any videos.

However, when the YouTubers discussed traits or their personal experiences, the focus was on the negative side. Some keywords that were brought up were depression, (*utsubyou*, in three videos), a general sense of difficulty in living (*ikidzurasa,* in three videos), and social withdrawal issues (*hikikomori*, in one video). The traits that were discussed (which will be analysed in chapter 4.2.4) were typically depicting autism as a disorder. Nonetheless, the difficulties the YouTubers experienced were usually contextualized and combined with suggestions of ways to cope with them.

A few of the videos discussed motivations for being public with the diagnosis, which usually included a desire to connect with other autistic people. Three of the videos, by Kurumi, Atsurou and Shiori, were 'coming-out videos', where the YouTubers revealed to

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[14] Japanese: *"hanashikata no tokuchou"*

their subscribers that they are autistic. While especially the videos by Kurumi and Shiori portrayed a high sense of shame, the decision to be open about autism shows that they wanted to increase autistic representation. Existing ties to other autistic people were not discussed in detail, but possible online communities were touched briefly when Arufu (2017, 0:30) mentioned internet discussions, Shiori (2018, 1,04) mentioned other *hattatsu shougai* YouTubers and Rei (2020, 2:02) mentioned internet content and videos on autism. Autistic communities where connections are made might not be common now but there seems to be a need for them. Neurodiversity was not discussed in any of the videos, but perhaps with the advent of more autistic communities, the ideas that challenge the medical model would become more common.

4.2.3. Sources of challenges and the suggested solutions

This chapter analyses whether the YouTubers depicted the source of challenges as autism itself (essentialist view/medical model), or the interplay between the autistic person and the environment (constructivist view/neurodiversity model). When desired courses of action were discussed, changing the autistic person (with medication or cure, for example) is linked to the medical model, whereas accommodation (support, inclusion, awareness) is part of the neurodiversity model. In the sample, the medical model was the more common portrayal of the sources of challenges. This is similar to Angulo-Jiménez and DeThorne's study (2019, 582) where 87% of the YouTubers said their challenges directly resulted from autism. However, when it comes to solutions, most Japanese YouTubers recognized the opportunities of other people, such as family, friends and employers in accommodating autistics in addition to their own increased effort.

Autism was named as a significant reason for difficulties in relationships. Shiori discussed how much she caused trouble for others. She blamed autism for difficulties in her earlier relationships and encouraged the autistic viewers to research and understand the condition so that they "won't cause trouble to others[15]" (2020, 7:24). While she was correct that autistic people can improve their relationships with their effort, her portrayal of the problems was one-sided. Neurodiversity model would recognize relationship problems as an incompatibility between the people involved.

Another example where autism is the main source of distress for the autistic person and those around them was in Atsurou's video. Atsurou's wife suspected having had a Cassandra syndrome[16] due to Atsurou's communication and attention difficulties. She said she has not been "checked for it (2020: 13:55)[17]", indicating this would be a medically recognized category, which it is not. The syndrome, which was coined by *Families of Adults Affected by Asperger's Syndrome*, is described followingly:

> *"Family members of individuals who have social disorders, such as Asperger Syndrome or sociopathy, generally suffer ongoing psychological trauma. The damage is insidious may continue for decades. If professionals fail to recognize damage produced by chronic, intimate exposure of a neurotypical individual to a family member with an autism spectrum disorder, the lack of validation creates extreme internal conflict, moral distress, loss of self-esteem, frustration, depression, and/or other symptoms […] (FAAAS, 2010)."*

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[15] Japanese: *"aite no hito ni komarasenai jouni"*

[16] Japanese: *"kasandora shoukougun"*. Also known as 'Cassandra phenomenon', 'complex' or 'metaphor' in English.

[17] Japanese: "*mite morattenai*"

The Cassandra syndrome, which FAAAS also calls ‘ongoing traumatic relationship syndrome’, frames autism as the source of trauma and mental distress in (essentially voluntary) romantic relationships, rather than the differences in communication, expectations, or showing emotion. Blaming autistic people for causing emotional distress for not meeting expectations constructed in a majority neurotypical society is not justified. While undoubtedly autistic partners can also be abusive, in those cases too, *autism* is not the source of stress or trauma but *abusive behaviour*.

However, despite discussion of the Cassandra ‘syndrome’, Atsurou and his non-autistic wife suggested ways how a non-autistic partner can help make the situation better for both. The best solution was for both to put effort into the relationship, and for the non-autistic partner to have flexible expectations of the other’s behaviour, framed as “it is what it is” and being relaxed (2020, 16:38-16:45[18]). Compared to Shiori’s view earlier where the challenges were solely caused by autism, Atsurou and his wife showed that the effort needs to go two ways.

Other people, more specifically their lack of awareness and understanding, was mentioned as a source of challenge in Ayano’s video. Ayano (2017, 4:10; 5:01-5:13) struggled when her mother did not believe she would have Asperger’s syndrome, as her permission was necessary to go to the hospital to get a diagnosis. This suggests that the lack of awareness in other people causes problems, which supports the constructivist views of disability. Rei (2020, 3:18-36) said that she aims to show things about autism that are ‘interesting[19]’, because that makes people want to know more and like autism. This

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[18] Japanese: ”*shouganai*” and “*ochitsuku*”

[19] Japanese: ”*omoshiroi”*

conceptualisation of autism around curiosity towards difference aligns well with the goals of the neurodiversity movement.

Kurumi (2020, 0:40-48) specifically asked non-autistic people to not treat her any different than others. This could be a sign of self-determination, however, she had a lot of shame about her condition and put a lot of energy into maintaining her appearance as 'normal', such as committing to daily medication. Her video was particularly interesting because, in the end, she added a clip of herself attempting to host the channel without medication. This was a powerful contrast to the beginning of the video. However, the captions of the video were very apologetic and anticipated people would get frustrated listening to her stumble on her words. Kurumi (2020, 8:03) encouraged people to skip to the end if they were feeling annoyed. Seeing how difficult certain everyday situations were to her, it is surprising how none of the solutions she suggested included accommodations from other people. The locus of the problem and the solution was the autistic person alone.

Rio (2020), who was specifically struggling with employment-related issues, was critical about society and common misconceptions about disabilities. First, she wanted the society to understand that not all disabilities are physical. When she explained her disability to the employers, their reaction would often be "it's fine, because the disability isn't physical[20] (2020, 7:41)". Because Rio found her own explanations of her conditions limited, she wanted more awareness in society (2020, 9:01). Nonetheless, even though Rio asked for accommodations and awareness, which is part of the neurodiversity model, she did not discuss how the environment is actively disabling. Neurodiversity model, similar to the social model of disability, says disability is constructed in the incompatibility of the person's needs and what the environment offers.

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[20] Japanese: *"shintai shougai janai nara daijoubu"*

In summary, while the majority discussed autism to be the source of challenges, most recognized the role of attitudes, awareness, and accommodations in overcoming hardships. They did not ask for as radical changes in conceptions of autism, but they recognized what other people can do to help. Difficulties such as high sensory stimulation related to the infrastructure or public spaces were not discussed, and instead most focused on interpersonal relationships. The narratives seemed to confirm the argument of Teruyama (2014, 141) on how the narratives tend to remain subjective and introspective rather than to stand up against society.

4.2.4. Description of autistic traits

Most videos focused on autistic traits and explaining them to viewers new to autism. Many YouTubers described the traits in terms of lack of something and directly linked these traits to struggles in everyday life. These terms included ‘deficit’ (*fusogu*), ‘poor at [something]’ (*nigate*) or inability to do something, for example, the inability to read subtle cues and mood in social situations (*kuuki ga yomenai)*. These are part of the medical model.

Some YouTubers displayed shame and insecurities about their traits. Kurumi, who also has dyscalculia[21] showed a clip of herself struggling to read a price tag. This was captioned with “I am hating myself[22] (2020, 9:06)”, showing a very negative attitude towards her own traits. This was despite her having asked other people to treat her traits just as individual quirks[23] (2020, 0:30; 02:34), which is a neutral depiction of the traits as differences.

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[21] difficulty to understand numbers and math, sometimes comorbid condition with autism

[22] Japanese: *“jikoken’ochuu”*

[23] Japanese: “*kosei*”

However, a few YouTubers occasionally challenged the disorder narrative and reframed autism around something positive. Arufu (2017, 8:21) discussed the autistic trait to always discuss the same topics as something with both good and bad sides[24]. People around him remembered his passions easily, which he considered positive. Atsurou gave a few examples of positive traits, such as sensitive hearing. He would notice rain or sounds from another room faster than his non-autistic partner (2020, 4:14-30). Atsurou (2020, 6:32) also said that as there are people of different heights in this world, there are people with different 'quirks[25]' or 'traits'. Comparing autistic traits to something neutral such as height, as well as seeing the positive sides, fall into the narrative of difference rather than a disorder.

Some YouTubers reconceptualized and destigmatized autistic traits through humour and laughter. For example, in Atsurou's video, the typical inability to understand sarcasm was reframed as a positive trait. The video had a caption: "I don't feel stress as I can't sense sarcasm[26] (2020, 13:25)." Atsurou and his partner laughed while explaining this. Katsu (2019, 2:08-2:38) used some examples from his own life and laughed when he told about his mistakes in social situations. This could be a form of self-deprecating humour, but laughter also brings sympathy and decreases the seriousness of these autistic traits.

Arufu's (2017: 3:10) observation of autistic people 'being too close[27]' to other people was interesting, as it highlights how autism is understood differently in different contexts. In the West, the stereotype is that autistic people are too distant and refuse to hug others (for example, Daily Mail 2020). In Japan, where personal space is typically larger, the inability to read subtle social cues often leads to autistic people being too close to people. This

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[24] Japanese: "*kore wa ii tokoro mo warui tokoro mo atte*"
[25] Japanese: *"kosei"*
[26] Japanese: *"hiniku wo kanjitoru koto ga dekinai node amari sutoresu wo kanjinai"*
[27] Japanese: *"kyori ga chika sugiru"*

observation does not answer the research question but is an additional observation that proves the social construction of autistic traits.

In Angulo-Jiménez and DeThorne's study (2019), 'description of autistic traits' category had the highest prevalence of the neurodiversity model, but it was not as noticeable in this sample. Overall, while most descriptions of the traits focused on the medical model, the narrative of difference was also noticeable. This included ways to see special interests, sensory sensitivity or inability to understand sarcasm as a positive rather than negative, either for the autistic person or people around them. However, there were also depictions of shame and self-hate towards autistic traits.

4.2.5. Allocation of autism expertise

Many videos that discussed autistic traits suggested that those who the traits fit would get assessed by a medical professional (for example, Arufu 2018, 10:51). Self-diagnosing was not said to be an alternative to official diagnosis, but an important first step. For example, Ayano (2017, 0:15-0:27) told she first self-diagnosed herself, which she later confirmed with an official diagnosis. This shows that one can have the expertise to successfully self-diagnose. In addition, Miiko and Katsu admitted that they did not have an official diagnosis (they had for ADHD), but have been either suspected with autism by professionals or have autistic tendencies (Miiko 2019, 0:25 and Katsu 2019, 0:54). This shows that autism knowledge is not exclusive to medical practitioners.

Four out of the five videos which discussed autistic traits as the main topic drew their information from medical studies or common stereotypes (Arufu, Hiromi, Miiko and Katsu). However, they all emphasized that autistic traits do not apply to everyone. Arufu, for example, questioned the applicability of stereotypes to himself and other autistic people he knew:

> "*People with Asperger's syndrome don't laugh, […] or can't carry on a conversation at all, perhaps some people have this kind of impression. But amongst autistic people, there are some who laugh very often or have very rich expressions…*[28] (1:29 – 1:50)"

He and the other three YouTubers had a critical approach towards medical studies and common conceptions, but only when it comes to the universal applicability them. They did not criticize the lack of autistic contribution to medical studies or biases as a problem.

Hiromi's video discussed the 'Aspergirls' book by Rudy Simone (2010). This book, and thus the video, is critical towards common diagnostic criteria which are based on the traits in boys. Hiromi (2019, 14:41) explained that due to this bias, women take longer to get diagnosed. Women often get diagnosed first with some other condition, and Hiromi was first diagnosed with depression as well (2019, 15:02). This stance is clearly showing that the current medical system is not doing its best for women, but Hiromi did not explicitly request any solutions, such as more research on autistic women and better education for doctors.

The usefulness of learning from other autistic people was discussed in two videos. Rei (2020, 2:15) says she was saved by the internet[29], and for her, this was an inspiration to start her own YouTube channel. Similarly, Shiori (2018, 1:04-20) explained how she decided to

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[28] Japanese: "*asuperugaa shoukougun no hito wa warawanai toka, […] kanzen ni kaiwa ga naritatanai toka, sou iu inshou wo motteiru hito ha moshikashitara iru kamoshirenai desu keredo mo, asuperugaa shoukougun no hito no naka demo, sugoku yoku warau toka, hyoujou yutakana hito tte iu no wa imashite…"*

[29] Japanese: "*intaanetto tte iu mono ni tasukete kitandesu yo"*

reveal her *hattatsu shougai* on YouTube after having watched other autistic people do so. Thus, not only did they praise other autistics as a source of expertise, but also of confidence and inspiration.

Rei (2020, 2:32-3:16) specifically said that she wants non-autistic people to watch her videos to understand autism better. This is an example of taking the role of authority on autism expertise. However, even when not specifically mentioned, it can be assumed that all YouTubers consider their videos as opportunities of education for both autistic and non-autistic people, as YouTube is a public forum accessible for everyone. Posting a video on autism from the first-person point of view is challenging the medical professionals as the only source of expertise. However, the overall impression was that autistic expertise was not considered as better, but only complementary to the medical professionals.

5. Conclusion

This research investigated if, and in what ways, do the Japanese autistic people on YouTube challenge the medical model of autism. The narrative analysis showed that the medical model is not explicitly criticized. The Japanese autistic YouTubers subtly challenged the medical model with constructivist ideas in the following ways: first, occasional use of nicknames for autism created in autistic communities. Second, a critical stance towards universal applicability of the common autistic traits or stereotypes. Third, occasional reframing of autistic traits as something positive. Fourth, understanding the opportunities of non-autistic people to accommodate. Fifth, and most importantly, becoming an authority and a voice of autism, as well as praising other autistic YouTubers for doing the same. The research also looked at whether the YouTubers showed signs of awareness of the neurodiversity model, which was not the case.

The significant increase of videos on autism made from a first-person perspective in the past few years shows that autistic people in Japan are becoming encouraged to discuss their experiences and fight the stigma. It also shows that while autistic communities in Japan are few, the demand for autistic voices and autistic communities is in increase. Future research could revisit the topic to find out whether this trend has remained, and whether increased contact between autistic people in Japan leads to more critical stances towards the medical model.

This research is an important contribution to the first-person views on autism, which have been lacking in research. Nonetheless, the voices in this research cannot be considered to represent the entire autistic population of Japan. The first reason is the small sample size. During the sampling period, no more than 10 autistic YouTubers (including two who only have an ADHD a diagnosis) could be found. Second, the demographics of the sample were skewed towards ‘high-functioning’ autistic people, women, people in their 20s or 30s, and those who were diagnosed in recent years rather than childhood. Third, YouTube will attract the most outgoing and verbally fluent people. Those who spoken word is challenging, will most likely not create content on YouTube. Therefore, future research should investigate autistic communities also on different type of platforms.

Increased awareness of the neurodiversity model could be beneficial for the Japanese autistic people. By not considering autistic people as ‘broken’ or deficit of skills, it lessens the stigma, empowers, and gives more possibilities of accommodations. The sample included people who experienced shame and stigma, which was clear from how they had kept autism a secret for long and struggles due to the negative view on ASD. As Japan copes with decreasing workforce, understanding the abilities of autistic people is beneficial both for autistic people and the society in large.

The lack of contact between the English and Japanese speaking communities was clear in the sample. Future research should find out whether instead of the neurodiversity model there are local variations of constructivist understandings of autism. Neurodiversity model is not the only positive conception of autism. Neurodiversity has its problems, for example, grouping all autistic people into one group, where the loudest voices belong to the highest functioning. In addition, treating the neurodiversity model that is born in an English-speaking context as the ideal for Japan shows a Euro-centric bias. Although it was not clear in this analysis, it is possible that Japanese autistic people have or will create with a conceptualisation of autism that is different from the neurodiversity model, but also challenges the medical model and empowers the autistic people.

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[30] Name: Atsurou

[31] Name: Rei

[32] Name: Kurumi

[33] Name: Katsu

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[34] Name: Rio

[35] Name: Hiromi

[36] Name: Shiori