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Disability- and Mental-Distress-Related Vlogs as a New Form of Life Storying (manuscript)[1]

This paper was part of Prof. Dr. Eveline Kilian's class 'Contemporary Life Writing' at Humboldt-Universität Berlin

<u>Introduction</u>

In this paper, I will share some results of my current research project *Shame as a Performative Narrative Affect in Automedial Art by Female British Authors with 'Disabilities' and 'Mental Distress'*, which is funded by the Deutsche Forschungsgemeinschaft (German Research Foundation).

1. <u>History and Cultural Significance of the Video Blog as Autobiographical Genre</u>

YouTube vlogs have only recently been investigated as a form of life writing. Before, they were analysed as 'transparent' data collections about authors' identities and behaviours, as forms of online activism, 'identity work, play, media-making, self-expression' (Maguire 2018, 10). Emma Maguire, however, states that vlogs are 'not direct channels to the '"true selves" of their authors' and that vloggers use strategies of representation and mediation for specific purposes (12). She describes vlogs and other social media products as 'cultural texts that are doing cultural work' (4). They not only tell us something about the authors (they may tell us very little about them) but they also / primarily reflect on, negotiate or challenge cultural representations of identity categories like gender, age, race, ethnicity, sexual orientation, religion, ability / disability and mental distress. The most important functions of personal vlogs listed by Griffith / Papacharissi (2010) and Maguire (2018) comprise:

- self-presentation, self-branding (in line with the 'broadcast yourself' agenda of YouTube)
- entertainment
- receiving / giving attention and validation
- performative / experimental identity formation
- communication
- generating impact
- community formation

- self-reflection / reflection on media content
- memory storage

In connection with YouTube's chronological template, the function of memory storage makes personal vlogs / YouTube channels autobiographical texts by default, even without their author's intention: content creators may vlog about professional and political topics and fields of interest (not so much about their lives) but the template of YouTube automatically produces a chronological (life) narrative.

Social media products like YouTube do not represent egalitarian, unbiased spaces (Nakamura 2014; Maguire 2018, 89-90). They use generalised templates and algorithmic operations that uphold patriarchal, gendered, ableist, heteronormative and racialised structures and value systems. Although blogs and vlogs depend on material / economic conditions, algorithms and templates that prevent full accessibility of content and buttress non-egalitarian social structures (e. g. inaccessible for persons with learning disabilities), scholars have described them as potentially empowering products of a participatory culture.[2] They provide space for experimental forms of self-presentation, the sharing of information on different topics, of personal opinions and stories as well as for the formation of precarious online communities and online forms of disability activism.[3] Emma Maguire sees blogging as a manifestation of a democratization trend within social media: almost everyone who has an opinion can find a platform to voice it in this 'new' media landscape (2018, 2). However, there are large economic and disability-related access barriers excluding people with cognitive and learning disabilities (Ellis 2010; Ellis / Goggin 2014; Ellis / Kent 2017).

Emma Maguire emphasizes that YouTube is a heavily commercialized, pop-cultural entertainment platform that follows a 'broadcast yourself' agenda: vloggers use self-branding and turn themselves into commodities. On social media, the circulation of media products is characterized by a blurring of the roles of 'producer' and 'consumer' for which Axel Bruns has coined the term 'produser' (Maguire 2018, 87). In online media economy, survival is measured in video views, subscriber tallies, likes and shares. In the saturated market of social media, attention is a desired goal that is hard to attain (Maguire 2018, 88). Content creators can choose to find sponsors for their videos or / and to monetise them and to have advertising appear in conjunction with

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[2] Anarbaeva 2016, 4-5; van Dijck 2009, 42.
[3] Bitman 2021.

their videos. The more people watch a video, the more click on the ad and the more income is generated per click. This commercial appeal and the competition for views can cause disabled vloggers (esp. those who want to create significant income) to sensationalize / 'flaunt' their disabilities or to hide 'unpopular', 'boring', consumer-unfriendly aspects of them. Vlogs receiving many views are mostly produced in HD quality and are often conspicuous: vloggers create interesting banners and icons for their channels and flashy thumbnails and titles to advertise their videos. Such marketing strategies have an impact on the representation of disability: some vlogs show that life with a disability can be worth living, provided you have the necessary social, financial and medical support, and that difficult times (illness, pain) can be followed by better ones. On the other hand, vlogs about disability, chronic illness and mental distress can create new body norms: many successful disabled vloggers are young (under 40), attractive and eloquent. However, there are disabled vloggers who do not completely / not always fit this type: Jessica Kellgren-Fozard (*Jessica Kellgren-Fozard* 2011-2022) makes very 'glamorous' as well as 'unglamorous' videos, the latter depicting phases in her life when she was unwell / in pain.[4]

Not least because of its heavily commercialized, attention-driven format, YouTube vlogs do not provide transparent, authentic portrayals / data about of the vlogger but show vloggers who perform roles to gain views, an aspect I will expand on later. The authors whose vlogs I introduce in my presentation have received medical diagnoses and define as 'disabled', 'chronically ill' or 'mentally distressed': Jessica Kellgren-Fozard (born in 1989) is a British YouTuber, disability and LGBTQ+ activist and television personality (known to viewers from her appearance in the TV show *Britain's Missing Top Model*). She identifies as lesbian, femme, Deaf and partially sighted. She has Ehlers-Danlos syndromes (EDS), a connective tissue problem, and Hereditary Neuropathy with Liability to Pressure Palsy (HNPP), a neurological condition.[5] As a result, her body bruises very easily, she often experiences a sudden paralysis of her extremities, e. g. after standing for too long, and a dislocation of her joints. As she

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[4] Jessica Kellgren-Fozard: 'What is Brain Fog?' 24 November 2016. Web. 21 January. 2022. <https://www.youtube.com/watch?v=LGDp7CsB3PQ&t=247s>;
Jessica Kellgren-Fozard: 'I Filmed My Chronic Migraine // Christmastide Day 11' 7 January 2019. Web. 21 January 2022. <https://www.youtube.com/watch?v=gUTeH7G8JAw&t=342s>.
Jessica Kellgren-Fozard: 'Why I Film When I'm Not Feeling Good // Vlogmas 2019 Day 13' 15 December 2019. Web. 21 January 2022. <https://www.youtube.com/watch?v=kXgiph8L-Qc>.
[5] Jessica Kellgren-Fozard. Web. 21 January 2022. <https://jessicaoutofthecloset.co.uk/press>.

shows in her videos, her conditions affect her entire body, causing chronic pain, chronic fatigue, migraines, brain fog, disorientation and memory loss. Claudia Boleyn (pseudonym) (*Claudia Boleyn* 2013-2022) is a British musician, writer and vlogger with a British-Indian background. She identifies as bisexual and as was diagnosed with anxiety, emetophobia, depression, BPD (borderline personality disorder) and ADHD (attention-deficit hyperactivity disorder).[6]

2. Features of YouTube Vlogs

In the following, I will discuss some of the most important features of YouTube vlogs (Smith / Watson 2014; Griffith / Papacharissi 2010; Maguire 2018) and give examples from *Jessica Kellgren-Fozard* (2011-2022) and *Claudia Boleyn* (2013-2022)

2.1. Commercialization, performance, entertainment

Many vloggers (esp. those with bigger channels) are open about the commercial aspects of their videos and about the fact that they are / sell a commodity / brand and are entertainers. Some, especially among those who create content about disability, illness and mental distress, also see themselves in the role of educators, e. g. about their disabilities and mental distress or about the role of disabled people in history[7]. Jessica Kellgren-Fozard states that she creates her main income through her videos, selects sponsors carefully and devotes a lot of time in her videos to advertise products she is likes / wants to recommend. Some of these products are related to her disabilities / chronic illnesses (e. g. in her video recommending her powered mobility aid).[8] She has a shop tab in her channel and a Website ('Jessica out of the closet') with a merch store through which she sells her products.[9] Many vloggers respond to their audiences' desire for 'authentic' content about living with disabilities and chronic illnesses but they also deconstruct, parody and thwart such expectations, engaging self-consciously and self-reflexively in performance / role play (more on this later). Kellgren-Fozard represents her disability and chronic illness symptoms (including brain fog, chronic pain and memory loss) by using different strategies. Sometimes, she uses

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[6] Claudia Boleyn. Web. 22 January 2022. <https://www.claudiaboleynofficial.com/>.

[7] Jessica Kellgren-Fozard: 'The Crippled Suffragette' // Rosa May Billinghurst // Historical Profiles [CC]' 24 March 2020. Web. 21 January 2022. <https://www.youtube.com/watch?v=9RuL6Y6BcGs&t=29s>.

[8] Jessica Kellgren-Fozard: 'I found my unicorn! // Mobility Aids 4 [CC]' 26 November 2019. Web. 21 January 2022. <https://www.youtube.com/watch?v=pnUJc8vSlns&t=274s>.

[9] Jessica Kellgren-Fozard. Web. 21 January 2022. <https://jessicaoutofthecloset.co.uk/>.

a 'realist' style and the practice of oversharing[10] personal information, filming herself in states of acute pain and 'brain fog'. Thereby, she intervenes into the heteronormative, ableist representation of female bodies in mass media. At other times, she uses a very stylized form of representation with an ironic edge,[11] thereby thwarting viewers' desire for 'authentic', 'raw' content, emphasizing the significance of her control over her self-representation and especially over representations that comprise potentially shame-related states of debility, pain, cognitive dysfunction and mental distress.[12] Claudia Boleyn uses similar forms of self-performance and role-play. She makes unscripted videos using a confessional, chatty style (using no / few cuts) in states of extreme mental distress / during breakdowns[13] to air the stigma of mental distress, to lower the threshold for discussions about such topics and to make others in such situations feel less alone (see more below) but such videos are no 'spontaneous' disclosures of an 'authentic' self. She refers to herself as someone who imitates / identifies with other personas. She explains that the last name 'Boleyn' is not her real / birth name and that she chose it because she identifies with Anne Boleyn, 2nd wife of Henry Tudor. She relates this 'role play' to her BPD and her feeling that she lacks a stable sense of self (quoting and seemingly affirming one of the pathologizing criteria of the *Diagnostic and Statistical Manual of Mental Disorders* 5)[14] but in her videos this role play appears as an experimental form of self-performance, not as a pathological symptom. In her video 'Vlog: I want to talk about trauma',[15] Boleyn is a 'traditional', self-reflective autobiographical narrator who looks back on her past life and past self (a typical autobiographical mode) and thereby establishes narrative continuity in the episodic narrative structure of the video blog. She uses meta-narrative commentary, referring to her verbal diaries, her processes of video making, uploading, non-uploading / video privatization, reflecting on her storytelling, e. g. on information gaps and topics she finds too difficult to share. In her YouTube channel, Boleyn performs different social

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[10] Sykes (2017), 151. See e. g. Jessica Kellgren-Fozard: 'What is Brain Fog?'; Jessica Kellgren-Fozard: 'I Filmed My Chronic Migraine // Christmastide Day 11'; 'Why I Film When I'm Not Feeling Good // Vlogmas 2019 Day 13'.

[11] Jessica Kellgren-Fozard: 'Things you should know about migraines... [CC]' 28 Aug 2019. <https://www.youtube.com/watch?v=p4ZPLpSgMMo&t=168s>.

[12] Corrigan 2014.

[13] Claudia Boleyn: 'An Update', 30 Aug 2021. Web. 21 January 2022. <https://www.youtube.com/watch?v=t9PKeYX4Abk&t=1s>; Claudia Boleyn: 'Just Talking'. 21 Sept 2021. Web. 21 January 2022. <https://www.youtube.com/watch?v=vj7l0sMcTB0&t=125s>.

[14] Claudia Boleyn: 'Living With BPD (Emotionally Unstable Personality Disorder)' 7 Nov 2016. Web. 21 January 2022. <https://www.youtube.com/watch?v=TeZn3kLXpyo&t=121s>.

[15] Claudia Boleyn: 'Vlog: I want to talk about trauma' 6 Dec 2021. Web. 21 January 2022. <https://www.youtube.com/watch?v=86PJJwmVUaY&t=843s>.

roles (concept: Erving Goffman) that become visible in the playlists: the roles of feminist activist, political commenter, young academic, Dr Who and Anne Boleyn fan. She states that her focus on subjects like fandom, politics and feminism is a survival strategy that distracts her from her mental distress. Furthermore, she appears in the social role of a psychiatry user / client in (talking) therapy, selecting her audience as listeners / therapists. She identifies with the literary character of the Lady of Shalott (from the 1832 ballad by Alfred, Lord Tennyson, depicted in the Pre-Raphaelite painting by John William Waterhouse, 1888). Boleyn states she recognizes the portrayed anguish, showing a copy of the painting in her video 'My ADHD and BPD diagnosis (stigma, reactions, shame?)' (7:23).[16] Boleyn also casts herself in the social roles of an 'educator' about her mental health conditions and of a mental health activist who shares her expertise and experiences with diagnoses and therapies, gives advice and answers viewer questions (e. g. in the video 'My ADHD and BPD diagnosis (stigma, reactions, shame?)'). Showing herself in an extremely vulnerable state during a breakdown in her video 'An Update', a state that most people would find too shame-inducing and risky to share online, she wants to raise awareness about the unavailability of social and medical support in states of crisis due to the severe underfunding and understaffing of the British National Health Service. Furthermore, she critiques the stigmatizing, severely gendered, sexist diagnostic criteria of BPD[17] that pathologize purportedly 'unfeminine' behaviour in women (aggression, impulsivity, promiscuity)[18] and talks about the moral stigma of personality disorders, about being considered a 'bad', 'aggressive', 'manipulative' person, a person who is to blame for their 'bad' character / behaviour. However, she is very positive and uncritical about her ADHD diagnosis (on the impact of this position see more below).

2.2. Hybridity

The personal diary vlog is a hybrid genre, combining life narrative with elements of travelogue, life style report, self-help literature, media review / analysis, fandom, political and historical commentary and political activism (see *Jessica Kellgren-Fozard* 2011-2022 and *Claudia Boleyn* 2013-2022). Hence, vlogs present selves that have multiple interests / multiple intersectional identities and multiple social roles. Many

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[16] Claudia Boleyn: 'My ADHD and BPD diagnosis (stigma, reactions, shame?)' 12 Nov 2021. Web. 21 January 2022. <https://www.youtube.com/watch?v=StCeehVvaic>.
[17] Claudia Boleyn: 'Living With BPD (Emotionally Unstable Personaliy Disorder)' 17 November 2016. Web. 21 January 2022. <https://www.youtube.com/watch?v=TeZn3kLXpyo>.
[18] Wirth-Cauchon 2001.

vloggers use new, hybrid forms of disability activism in combination with life-storying formats with the intention of de-stigmatizing / 'normalizing' disability / mental distress and of educating and entertaining their audience. Jessica Kellgren-Fozard explains her strategy of 'soft activism' in an interview on Sky.[19] She states that soft activism is a practice enabling disabled persons to share and validate their stories and experiences, to overcome their isolation, to engage in community building, to 'normalize' / de-stigmatize disabilities and technical aids by including representations of disability and chronic illness in general life style content that is not primarily about disability / chronic illness but is accessed by a large number of viewers that would not watch content limited to disability / illness-related topics. Through this technique, she hopes to raise awareness about living with disability / chronic illness among a larger audience in 'a roundabout way' (thereby avoiding to preach to the choir). Kellgren-Fozard's strategy of a 'normalisation' of disability shows that chronic illness and disability are ordinary aspects of life rather than pathological exceptions to a bio-medical rule / norm. [20] In addition, Kellgren-Fozard's large channel (over 80,000,000 views) represents disability as an intersectional category (a category intersecting with 'queerness' and 'femininity'), thereby successfully contesting stable, essentialist, ableist and heteronormative notions of 'normality' and 'disability'. She explicitly opposes an essentialist use of the term 'disability' that pits 'normal' against 'abnormal' when it comes to references of human beings[21] She de-familiarizes her viewers' ideas about 'normality' and 'abnormality', showing them to be relative, indeterminate notions. Viewers of her video on baking, titled 'My latest hospital visit in the form of a rainbow cake // AD [CC]',[22] watch her during a 'normal', ordinary (apparently heteronormatively 'feminine') activity but they can observe how she re-signifies (crips and queers) this activity by baking a symbol of queer pride (a rainbow cake) and by informing her viewers about her recent back injury that is connected with her chronic illness. In addition, she shares details about her difficulties to get access to treatment (the long waiting time to be able to see a specialist), thereby pillorying the difficult situation in the British health care system, especially the understaffing and underfunding of the British National Health Service.

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[19] Sky News: '#Divived. Sky News. 'I got online hate for not being disabled enough'. 18 April 2019. Web. 21 January 2022. <https://www.youtube.com/watch?v=u2NOeP2vxwE&t=638s>.
[20] Chiu 2019.
[21] Jessica Kellgren-Fozard: 'What IS Normal??? [CC]' 25 Oct 2016. Web. 21 January 2022. <https://www.youtube.com/watch?v=vmxXlpWW5zM>.
[22] Jessica Kellgren-Fozard: 'My latest hospital visit in the form of a rainbow cake // AD [CC]' 30 June 2020. Web. 21 January 2022. <https://www.youtube.com/watch?v=T7tXwaG9-WA>.

Furthermore, Kellgren-Fozard's vlog critiques the normativization of and the hierarchisation within a narrow concept of 'disability' that denies the experiences of disability and interdependency to people with 'invisible' disabilities / chronic illnesses and changing mobility / debility conditions and needs.[23]

2.3. Co-Createdness / affective amplification

YouTube videos are co-created, citational media products: vloggers collaborate with each other, cite other channels, other media products (books, mass media products, vlogs) and invite their viewers to suggest topics and ask questions. Hence, viewers co-create the content of channels and vlogs as well as website surfaces with their comments, numbers of views, comments, dialogues with authors and other viewers and their likes and dislikes. The increased upload of content on mental distress in Claudia Boleyn's channel is related to her breakdown and general mental health condition but it is also a response to her viewers' requests of such content. Boleyn states that such requests are often expressed in the form of traditional letters addressed to her letter box (she shares the address in her channel description).[24] Boleyn explains that talking about difficult (past) situations is empowering for her, it helps her to understand them and she hopes that it can help her viewers to feel less alone in similar situations, to understand more about mental distress, to question the stigma of mental illness and to see that people with mental distress are not 'monsters' but interesting, creative human beings.[25] In one case, the interaction between her video content and her viewers' responses (the members of her larger social media community) comprised practices of affective co-witnessing[26] and solidarity. It stopped an on-going harassment that the author was subjected to by her uncle and that was a major cause of her mental distress.[27] Boleyn had shared content on YouTube about

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[23] Jessica Kellgren-Fozard: 'Am I Disabled Enough? // ft. Hannah Witton' 29 March 2019. Web. 3 March 2022 <https://www.youtube.com/watch?v=YorlAb3q_hs&t=109s>; Jessica Kellgren-Fozard: 'The Guilt and Shame of Life Without a Diagnosis', 19 October 2018. Web. 3 March 2022. <https://www.youtube.com/watch?v=jrj9H6qK0mc&t=537s> and Jessica Kellgren-Fozard: 'Are You Disabled Enough? Physical Disabilities and Mental Health // Vlogmas Day 8' 8 Dec 2017. Web. 3 March 2022 <https://www.youtube.com/watch?v=L23tfjyjnkw&t=459s>.

[24] Claudia Bolen: 'Vlog: I want to talk about trauma' 6 Dec 2021. Web. 21 January 2022. <https://www.youtube.com/watch?v=86PJJwmVUaY>.

[25] Claudia Boleyn: 'Vlog: I want to talk about trauma' 6 Dec 2021. Web. 21 January 2022. <https://www.youtube.com/watch?v=86PJJwmVUaY>; Claudia Boleyn: 'Living With BPD (Emotionally Unstable Personality Disorder)' 17 Nov 2016. Web. 21 January 2022. <https://www.youtube.com/watch?v=TeZn3kLXpyo>.

[26] Richardson and Schankweiler 2019, 168-169.

[27] Claudia Boleyn: 'I am being threatened' 5 Oct 2021. Web. 21 January 2022. <https://www.youtube.com/watch?v=vtCg0pFlmjs&t=295s>. Claudia Boleyn: 'Bullies don't always win' 6 Oct 2021. Web. 21 January 2022 <https://www.youtube.com/watch?v=e_btLilER1c&t=361s>.

being harassed[28] and the harasser (her uncle) feared she might disclose further information about his abuse. Her viewers bore witness to these threats that were posted on social media, encouraging Boleyn to report to the police. As a result, her uncle is monitored and stops his attacks, at least on social media.

Another facet of the co-createdness of vlogs is the co-creating impact of algorithms. As Boler and Davis have shown, [29] algorithms create affective flows and loops that have a visceral impact on users through the suggestion of similar / formerly liked content. Hence, they create affective echo chambers that can in turn produce affective publics / felt online communities (Papacharissi 2015: 26, 29). As the example of affective co-witnessing in Boleyn's vlog has shown, affective publics practice solidarity and even protect the author from online bullying. Even in smaller channels (Boleyn's channel has about 4,000,000 views), algorithms create and amplify 'trends' through social (affective) contagion, yet this formation of trends and affective publics does not necessarily lead to a de-stigmatization of non-normative forms of embodiment or of mental distress. This can be observed in the comments to Boleyn's video 'I have ADHD',[30] in which she shares information about her ADHD diagnosis. The video received more views than her other videos uploaded around the same time (1800 views compared with 1300-1500 for other videos from October-November 2021) and 54 comments (more comments than usual). 23 commenters mention their own ADHD or BPD diagnoses, 5 commenters state that Boleyn or YouTube played a role in their being diagnosed with ADHD or BPD. This sharing of common experiences about psychiatric diagnoses may appear like a practice of solidarity, a form of community building that seeks to de-stigmatize mental illness. Unfortunately, however, it has the opposite effect. It amplifies / proliferates uncritical responses to a stigmatizing psychiatric label[31] that reinforces the medicalization and overmedication[32] of mental distress. Interestingly, whereas the majority of commenters do not critique but rather affirm psychiatric diagnoses without discussing the stigma attached to them or the financial profit gained through psychotropic medication that is facilitated by such

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[28] Claudia Boleyn: 'I am being threatened'. 5 Oct 2021. Web. January 2022.
<https://www.youtube.com/watch?v=vtCg0pFlmjs&t=295s>.
[29] Boler and Davis 2018.
[30] Claudia Boleyn: 'I have ADHD!' 1 Nov 2021. Web. 21 January 2022.
<https://www.youtube.com/watch?v=zUzP4RnqbPw&t=71s>.
[31] On the stigmatization of people who received a diagnosis of ADHD see Speerforck, Stolzenburg, Hertel et al. 2019; Masuch, Bea, Alm et al. 2019.
[32] Ophir and Shir-Raz 2020.

diagnoses, the comment by 'Jose Carlos Galindo' rejects a medicalization of traits and behaviours that psychiatrists and their clients associate with ADHD. Although his comment emphasizes similarities between his own and Boleyn's personalities, it refrains from a medicalization of personality traits and suggests instead that they are a sign of giftedness and not of ADHD.

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