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Article – Theme section

Genetic hauntings

Mediating pre-patienthood and haunted health on TV

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Abstract

Through the development of a "health hauntological" approach, this article investigates how pre-patient illness narratives are mediated and negotiated in and around the DR documentary series Gentesten ændrede mit liv (2020) [The gene test changed my life]. We argue that this documentary format attests to how the expansion of genetic testing technologies alters experiences, genres, and narratives of illness that increasingly move to a pre-diagnostic and pre-symptomatic domain. The analysis shows how the use of genetic testing technologies creates hauntological situations in which pre-patients – through the mapping of family pathologies of the past and possible future diagnoses – encounter the complex temporalities and entanglements inherent to genetic bonds. Furthermore, we claim that these haunting encounters with mortality, vulnerability, and potential loss can be acted on – or listened to – in various responsive ways. Mediating pre-patient illness narratives thus entails an ethical balancing between care for participants and the desire for tellable, transformational narratives.

Keywords

Genetic testing, pre-patient illness narratives, health hauntology, pre-patienthood

Introduction

Due to their father's medical history, Jakob and Mathias live with a permanent fear of blood clots, or venous thrombosis. Consequently, they decide to undergo on-camera genetic testing in the DR documentary series *Gentesten ændrede mit liv* (DR, 2020) [*The gene test changed my life*]. The results clear the older brother of the genetic disposition to develop multiple serious blood clots, but the younger brother, Jakob, *is* genetically disposed to the condition. Reflecting on the results, Mathias expresses a sincere wish that he had been the one with the "bad genes", in order to take over Jakob's heavy burden. Jakob himself airs a nagging doubt upon learning the results: "I'm wondering whether it was worth it for me to get this knowledge" (DR, episode 5, 11:44) (we have translated from Danish to English all quotes from the series included in this article). The case in point underlines how an individual sense of health and intimate family relations can be altered by genetic testing. It also underlines the ethical dilemmas of using such testing as a point of departure for televised documentaries. Genetic tests enact complex intertwinements of painful family histories, anxieties of pending illness, and questionable knowledge production and, thus, produce an intense existential situation which must be handled by the involved media.

Health managerial genetic testing, paired with notions of preventive action or even pre-symptomatic treatment, is often seen as an intriguing promise of increased agency regarding future states of illness and health. However, the current surge in personal genetic testing has been criticised by medicals who warn the public about overdiagnosis, excessive medicalisation, increased pressure on health care systems, and a crude optimism about the predictive possibilities of the new technologies (Green et al., 2020; Dalgas, 2017). The ambivalent promises and pitfalls of genetic testing play out in and around *Gentesten ændrede mit liv*. The series consists of six episodes that follow Danes who are undergoing genetic testing and counselling on TV. DR aired the series in the fall of 2020, but by December of that same year, they removed it from their streaming platform due to criticism from a group of prominent medical doctors (Gerdes et al., 2020; the series can still be accessed through the Mediestream archive). These doctors criticised the lack of expert guidance on the show as well as the practice of testing seemingly healthy individuals. The documentary and the ensuing controversy attest to how genetic testing not only produces new health practices and dilemmas, but it also prompts novel media formats, experiences, and discussions of illness and health. These new media texts engage with the increasing number of "patients-in-waiting" (Timmermanns & Buchbinder, 2010), or "pre-patients" living without any actual symptoms but with the knowledge of potentially impending diseases.

Research questions and approach

In this article, we ask:

- How are mediated experiences and narratives of pre-patienthood constructed in and around the documentary?

- What are the consequences and dilemmas of mediating existential situations in which the present is infused with knowledge of genetic heritage and potential future illness?

In investigating these questions, we take the six episodes of the documentary as our empirical starting point. To discuss the dilemmas of the show, we also include the newspaper op-ed that caused DR to remove the series from their platform. The documentary series is chosen as a case since it is the first Danish TV show to utilise and air health managerial genetic testing of Danish citizens. As such, the series not only exemplifies a new type of pre-patient illness experience, it also – not least due to the controversy it triggered – takes part in shaping how such experiences can, and cannot, be disseminated among the Danish public in the future. We treat the series as indicative of a cultural transformation "in-the-making" – in terms of how and when illness is experienced and narrated – and as an opportunity to discuss how media plays a role in shaping this transformation. We do not engage in a close reading of the entire series, but rather use instructive examples from various episodes to show and discuss the relevance of a particular "health hauntological" approach. Thus, the series is read both as representing larger cultural changes in terms of how to identify and experience illness and as a performative media text that affects how genetic testing can be embedded in future media formats. This cultural studies approach to the series and op-ed (Hall, 2003, 2006) allows us to reflect on how genetic technologies are currently changing and complicating notions of illness and health in a way that produces ethical dilemmas for media institutions and calls for new theoretical approaches.

Drawing on the concept of "hauntology" (Derrida, 1994), we propose a health hauntological framework to analyse the main consequences of the spread of health managerial genetic testing. Increasingly, genetic testing technologies make health ontologically indistinguishable from illness – as health is lived and navigated in relation to impending patienthood – and temporally complex in accentuating the ties to family pathologies of the past and the body's potential future diseases. Analysing the pre-patient experiences facilitated by the documentary as well as the subsequent media dispute sheds new light on how media participate in constructing and negotiating this rising state of pre-patienthood in which health is constantly "haunted" by impending illness. Taking a health hauntological approach to the documentary allows us to focus on how *temporalities* and *intimate relations* are complicated when genetic testing is used as a technology for producing tellable media narratives. Further, this approach allows us to discuss *ethical* dilemmas with regard to how the participants, and their future life, are cared for within the framework of the documentary.

Theoretical framework

Mediating genetic risk

Genetic research and developments characterised the twentieth century to the degree that it has been termed "the century of the gene" (Keller, 2000). Alongside the scientific discoveries, an informational discourse on the gene as the essential code of all life came to dominate the public understanding, the "fantasies and fears" of genetics – or what Sarah Franklin (2000) terms the genetic imaginary. Organic life, it was hoped and dreamed, could be read and understood through the mapping of the specific genome of each species. However, as both Franklin and Nicolas Rose (2006) have pointed out, this genetic essentialism is now, by virtue of the newest scientific discoveries, starting to shift towards a "post-genomic" imaginary in which the one-way model of genetic coding is substituted with a focus on complexity, intervention, and re-programming.

A new molecular-entrepreneurial genetic discourse entails an altered focus on genetic agency, gradually leaving behind the deterministic understanding of genes as unalterable codes. Nicolas Rose, for example, observes that "the genetic code is no longer thought of as a deep structure that causes or determines, but rather as only one set of relays in complex, ramifying, and nonhierarchical networks" (Rose, 2006, p. 130). Characterising this new post-genomic imaginary is an emergent paradigm of "genetic responsibility", where individuals are increasingly expected to know and take responsibility for the potential pathologies of their specific genetic code. Thus, personal genomics has become a central part of contemporary self-optimisation projects in "contemporary advanced liberal democracies" (Rose, 2006, p. 125). Rose continues:

> Genetic forms of thought have become intertwined with the obligation to live one's life as a project, generating a range of ethical conundrums about the ways one might conduct one's life, formulate objectives, and plan for the future in relation to genetic risk. (Rose, 2006, p. 129)

The incentive to know and manage genetic risks also leaves its mark in contemporary media culture.

Television researcher Sophia Bull observes that within the last three decades, television's interest in genetics has exploded (Bull, 2019, p. 1). Reading across a wide array of genres, including both fiction and non-fiction formats, she contends that the general shift towards a post-genomic discourse is still on its way in television's genetic content. "The televisual genetic imaginary of the early twenty-first century is still heavily saturated with *genetic essentialism*", she writes, while adding that "television has also begun to express a wider emergent *post-genomic imaginary* that voices ideas beyond the more traditional deterministic and essentialist understanding of the gene" (Bull, 2019, p. 14). The DR documentary is symptomatic of this gradual change. The basic premise of the show is to change the future of its participants through genetic knowledge and agency. However, the narrative build-up around the reveal of the genetic test results as a sort of diagnosis or

verdict, and some of the aesthetic elements still attest to a deterministic and essentialist understanding of genes.

An interest in genetic heritage has also characterised media formats beyond the televisual institutions. In the wake of the introduction of direct-to-consumer (DTC) genetic testing in 2007, there has been a regular surge in videos, vlogs, and posts on digital platforms, such as YouTube and Instagram, where vloggers and influencers share their gene testing experiences and results – often sponsored by leading DTC genetic testing services such as 23andme and MyHeritage. The majority of these social media texts focus on genealogical and geographical origins, and it has been suggested that this form of at-home genetic testing without health managerial goals can be described as "recreational genomics" (Felzmann, 2015, p. 23). However, a 2014 study of 20 YouTube videos about health-oriented DTC genetic testing shows how social media platforms also provide a new (semi-)public space where the formerly private genetic consultation is shared with followers and viewers of all kinds (Harris et al., 2014). The authors argue that the narratives told in these videos should be termed "autobiologies" – referring to the study and narration of one's own biology – rather than illness narratives, since "they are not stories about states of sickness and suffering, but are rather narratives of playfulness, possible to those 'in-waiting' who can afford a more casual engagement with the technologies" (Harris et al., 2014, p. 73). The authors do, however, argue that the narrative form and performance itself may be deeply influenced by the context and the platform investigated. This concluding point certainly seems confirmed by the documentary series investigated in this article. The narratives told by the six participants here are not playful and casual; they are heavily influenced by anxieties and apprehensions of illness and suffering. As such, we suggest terming them "pre-patient illness narratives" – a concept that challenges the notion in existing literature that illness narratives require the actual arrival of illness, symptoms, and patienthood.

Narrating illness before the fact

Traditionally, an "illness narrative" (or a "pathography") has been defined as "autobiographical accounts of illness spoken or written by patients" (Jurecic, 2012, p. 2). In this line of thinking, the narrator of illness narratives is linked to the role of the patient per default, which entails both that the narrative deals with serious illness (e.g., cancer, not a cold) and that the narrator is institutionally and socially acknowledged as a legitimate object of treatment and care. The serious character of the illness is important, because illness – in the illness narrative tradition – is understood to represent a rupture of normal life – a rupture that calls for narrative work in order to re-establish a sense of coherence, agency, and control in the life of the ill person. Arthur Frank programmatically outlines how the arrival of serious illness is the very requirement for initiating an illness narrative: "In the beginning is an interruption. Disease interrupts a life, and illness means living with perpetual interruption" (Frank, 1995, p. 56).

Existing research in the illness narrative tradition presumes that medical approaches to illness are insufficient, as they devaluate individual or lived aspects of being ill. The importance of illness narratives is therefore often outlined using a set of dichotomies – like patient/human, disease/illness, and body as object/body as subject. Medicine and health care seem to prioritise terms on the left side of the slash, while illness narratives focus on those on the right side. In medical treatment, the ill person is positioned as a patient with a generic disease that needs to be studied and targeted as an object of treatment. This leaves little space for the lived and complex human experience of interpreting and making sense of individual ailments. The idea that humans reclaim personal versions of illness in the illness narrative is, for instance, set forth by Frank (1995) to underline how illness narratives are told in opposition to the systemic approach. An important point in the existing literature is thus that although illness narratives prioritise human and subjective accounts of illness, they also – through their reliance on the dichotomies mentioned above – rely on the patient role and treatment processes offered by the health care system. Paradoxically, the entitlement to tell an illness narrative presupposes an institutional interpellation that can serve as a systemic counterpart to the illness narrative proper (Hawkins, 1999). In this article, we question this assumption by arguing that being a patient under institutional treatment is no longer the precondition for telling illness narratives. Now, they can be told in the light of more or less valid risk assessments that position the narrator as a potential or future patient: a patient-in-waiting, or a "pre-patient".

What we define as "pre-patient illness narratives" are narratives of illness experiences that are told in a *pre-institutional*, *pre-symptomatic*, and *pre-diagnostic* realm. This implies that the narrator has not been interpellated as a patient or as an object of medical treatment but still experiences and processes illness as an individual experience. With the development of genetic testing technologies, it has become possible to offer personalised risk assessments of potential illness. In other words, illness can be experienced as a virtual condition – something that might trigger a diagnosis and turn you into a patient in the future. The absent presence of illness in such a situation entails that illness becomes insecure and prognostic rather than immediate or linked to a current state of being. Thus, the fundamental experience of illness has been moved to a pre-diagnostic field and arrives as a risk assessment rather than as a diagnosis. While Frank is focused on the role of illness narratives in reinforcing "remission society" and its expectations of progression, overcoming, and restitution, pre-patient narratives orient us towards the current development of a prognostic culture of prediction, anticipation, and prevention. In this development, media and technology become increasingly involved in foreseeing and shaping future trajectories of action and life based on an analysis of data about the past and present.[1] According to Andrejevic, this culture of anticipation uses media to "identify a punch in process" (Andrejevic, 2019, p. 73) – a metaphor that is also useful in terms of understanding the documentary's attempt to predict and avoid illness before its symptomatic arrival.

Health hauntology

In order to grasp the changes in how illness is experienced and narrated from a pre-diagnostic position, we will develop and work from within a "health hauntological" framework. Hauntology, a pun on ontology coined by Derrida in *Specters of Marx* (1994), refers to the study of that which is not yet/no more there. Derrida unfolds the concept through the spectres of Marxism in post–Cold War Europe. His thoughts have primarily been used by literary scholars (Davis, 2005). However, the study of haunting also has strong links to forms of psychoanalysis (Abraham & Torok, 1994), sociology (Gordon, 2008), and affect theory (Cho, 2008; Blackman, 2012).

For several reasons, hauntology presents an innovative and interesting framework for the study of pre-patient illness narratives. First, the concept works in a deconstructive manner to problematise the binaries of ontological being and non-being – presence and absence. Hauntology, instead, engages with the potency, agency, and meaning of that which is only seemingly absent, dead, virtual, or non-present. As such, hauntology can be used to understand the current challenges to the hitherto dominant ontological way of thinking about the body, illness, and health (Blackman, 2008) presented by biotechnological developments and prognostics. When genetic testing reveals that health is never simply health but always already potentially disturbed by the family pathologies of yesterday and tomorrow, fundamental understandings of illness as experientially and ontologically distinct from health and as corporally individual are questioned.

In line with this, hauntology accentuates how the present is always influenced by and intertwined with the past and the future in various ways. The autonomy of the present is challenged, and the linearity of time is undone by thinking of and through a constitutive temporal complexity in instances of haunting. "If there is something like spectrality", Derrida writes, "there are reasons to doubt this reassuring order of presents and, especially, the border between the present, the actual or present reality of the present, and everything that can be opposed to it" (Derrida, 1994, p. 48). Hauntology and genetics share an evident focus on lineage, heritage, and genealogy, in that both concepts point to the unsettling agency of the past in the present. The dead – or the deadly genetic information – to which we are bound through family and history return to disturb the present in both cases. However, central to Derrida's notion of haunting is a double temporal orientation; haunting also pertains to the future, to the unknown of that which is yet-to-come. Thus, the hauntological framework makes it possible to consider the role of unknown futures in the emerging pre-symptomatic illness narratives as well: How are pre-patients directed to different pathological futures by new technologies? And how can the orientation towards prognostics and managing possible futures be challenged by an attention to the inherent unknowability and unmanageability of the future?

Finally, hauntology entails a relation of response to that which is haunting. Derrida terms this relation one of justice and openness to the yet unknown. However, sociologist Avery F. Gordon pinpoints the responsibility for responding when she states that "haunt-

ing, unlike trauma, is distinctive for producing a something-to-be-done" (Gordon, 2008, p. xvi). The hauntological call for action paired with new biotechnology might seem to echo current healthism, individualisation, and self-management ideologies – and health managerial genetic tests are certainly employed to this end by, for example, biohackers who try to "exorcise" the genetic spectres of illness and death. However, as the documentary shows, the haunting produced by genetic testing technologies is an unsettling phenomenon that prompts a plethora of uncertain responses and actions ranging from denial, anger, and attempts at exorcism/exercising to responsiveness, curiosity, and conversation. The genetic test is a technology that works to demonstrate how we are always-already tied to deceased others, to family members and loved ones of the past and the future – but this constitutive relationality and vulnerability may be interpreted and acted on differently. In the end, as Derrida writes:

> [The task is] to learn to live *with* ghosts, in the upkeep, the conversation, the company, or the companionship, in the commerce without commerce of ghosts. […] And this being-with specters would also be, not only but also, a *politics* of memory, of inheritance, and of generations (Derrida, 1994, p. xvii-xviii).

As such, hauntology helps us pay attention to how the response to a genetic test is not only a matter of individual illness and health projects, but also of how to deal with time, death, and vulnerability as unavoidable factors in present and future relations.

Building on these insights, we propose a new health hauntology that enables us, in the words of Franklin, to investigate the "changing relationships between health and pathology, disease and cure" (Franklin, 2000, p. 189). Contrary to Franklin, however, the hauntological line of thinking here provides a means of analysing the mundane experience of living in a temporally, ontologically, and affectively complex relationship to disease not yet present, but possibly pending in the pasts and futures of the body's genetic code. As such, we suggest refocusing health sociological and biomedical discussions of personal genomics from the biopolitical regulatory relationship between state, individual, technology, and imaginary (Rose, 2007; Franklin, 2000) to the more intimate, mundane, and lived experiences of genomic risk assessments. Donna McCormack's (2021) and Margrit Shildrick's (2021) works on organ transplantation – in which the transplanted organs are often sensed as a severe complication of bodily boundaries and of life and death – are rare examples of research engaging with this hauntological approach to health experiences. We contribute to this endeavour by focusing on genetic testing experiences as a crucial site for health hauntological analysis.

Analysis

The DR documentary series consists of six episodes, each focusing on one main participant. All participants – three men and three women – are Danish citizens. Hence, the

show's appeal is not the common curiosity generated by celebrity participation as seen in other forms of genetic entertainment (cf. Bull, 2019). Two participants fear different forms of cancer, one has a family history of multiple serious blood clots, and the remaining three participants worry about different forms of brain injuries or mental illnesses (Alzheimer's, bipolar disorder, subarachnoid haemorrhage). Four of the participants fear diseases that their fathers suffered or died from – thus tapping into a general paternal structure within genetic imaginaries (Franklin, 2000) – while the remaining two participants trace their genetic anxieties back to their mother and aunts. Family members and their stories of illness and suffering thus play a direct role for the participants and their motivation for engaging in the show. In this way, individual health is collectivised and distributed from the onset through notions of genetic heritage.

The series' two appointed experts – PhD in genetics Lasse Folkersen and general practitioner and celebrity television doctor Charlotte Bøving – are responsible for guiding the participants and viewers through the genetic test results and the following course of events. While Folkersen is cast as the careful scientist, Bøving takes on the role of the pragmatic and tough, but loving, family doctor. She is also the one to follow and guide the participants after they receive the test results. Each episode follows the same overall plot line within the show's 40-minute time frame: 1) the participant tells an emotional history of family illness, 2) the results of the genetic test are revealed, 3) the participant is followed for two or three months while trying to cope mentally and physically with the news, and 4) a concluding meeting with the experts sums up the overall (always positive) outcome of learning about individual genetic risk factors.

Health as genetic heritage

One participant, Vivi, has decided to participate because she fears she will suffer from subarachnoid haemorrhage like several of her close family members. Flickering through family albums in her living room, Vivi starts the episode by telling her family history of fatal or severely damaging haemorrhages in the brain. She wonders whether her father would still be alive if he had changed his lifestyle in time. This nagging question becomes the motivation for her own health project: "My lifestyle needs to change if my kids are going to have me around for a long time" (DR, episode 4, 06:15). Family history is central to Vivi's decision to have her pathological predispositions mapped. At the same time, Vivi expresses her experience of already living with severe illness as a constant, looming presence in her life. For example, whenever she has a headache, she fears that *now* the moment has come when an aneurysm has burst in her brain. According to Bøving's introductory voice-over, it has taken Vivi several years to summon the courage to take the genetic test. Even if Vivi is not actually ill, the expectation of serious illness makes her apprehensive and hyperaware of any somatic changes or "symptoms".

The experience of an already disturbed health haunted by both family heritage and potential future illnesses is typical of the pre-patient narratives told in the series. One

of the other participants, André, has even ruled out having children if he risks passing on the family's pathological genetic disposition – despite the fact that he is seemingly healthy and well-functioning. With the current genetic technologies and knowledge at hand, everyone not living with a diagnosed illness might, to some degree, be considered "pre-symptomatically ill" (Rose, 2006, p. 19): existentially healthy but experientially always-already becoming-ill. The six pre-patients in the show take elaborate precautions and show an intense somatic awareness of potential symptoms due to medical family narratives. Pre-patienthood is thus mediated as an ambivalent position, in which health is both distributed across the bodies of fathers, mothers, children, and aunts, but also lived as a personal experience of vulnerability and responsibility. Following Lisa Blackman, this shows how the genetic imaginary produces experiences in which we "extend into our environments and yet paradoxically are required to live this extension as interiority" (Blackman, 2012, p. 151).

The narratives of Vivi and the other participants are not classic illness narratives catalysed by the narrative wreckage of the individual diagnosis in the attempt to restore order and meaning in the present. Rather, they are narratives told from the perspective of the pre-patient, where precautions and worries shape the lives of those who are neither well nor sick. In this new biosocial category, illness and health blend into a life of susceptibility, and the present is continually haunted by the genetic past and potential pathological futures. In Vivi's case, the genetic test reveals that her fear of aneurysms and haemorrhages is well-founded. Even if, as Bøving admits, geneticists are not able to say anything qualified about the specific risk of burst aneurysms, Folkersen does identify genetic factors in Vivi's test regarding a metabolic syndrome that can potentially lead to cerebral haemorrhage. Vivi is composed but sad when she receives the genetic "news" that confirms her own bleak intuition. In the following scene, the show cuts to one of the simulated monologues so typical of reality television (Jerslev, 2014). Here, Vivi confides in the (inter)viewer that the first thing she thought about when she received the genetic test results was her sister and the moment she was taken away in an ambulance after suffering from a burst aneurysm in the brain. In that moment, she says, she realised that she was going to be next. Once again, the health hauntological framework is brought to the front as Vivi, immediately upon receiving her own prognosis, thinks of the intimately known and traumatic past of a close family member. The family past becomes Vivi's future as she interprets the genetic result through the visual recollection of her sister's stroke. Hence, a complex layering of temporalities and kinship is at play, as a disturbing *doppelgänger* motif is suggested (Blackman, 2008): The genetic "curse" makes the pathological repetition seem inevitable. Thus, the gene test not only collapses past and future; for a moment, it challenges the idea of the autonomous agential subject, as Vivi is implicitly condemned to repeat the family pattern laid out by her genes. Despite explicit reservations as to the predictive possibilities of the genetic test from Folkersen and Bøving, this scene certainly suggests that if Vivi does not take seriously her genetic susceptibility, she will end up

repeating the family history. The implicit diagnostic causality ascribed to the test through the juxtaposition of the result with the conjured image of the suffering sister suggests that the show draws on an essentialist genetic imaginary in which notions of genetic causality, linearity, and inheritance are dominant (Bull, 2019). This genetic essentialist discourse is underscored by the music and lyrics used in the introductory sequence of all six episodes: The participants are filmed in gloomy and rainy outdoor settings in the prosaic landscapes of wintry fields, lawns, or city streets. Piano music and a male voice singing the lyrics "feel me put my hands together. I pray for you" accompany the slow-motion footage. The religious gesture and second-person address of the lyrics reinforce a sense of fatalism and suspended individual agency.

However, the suspension of agency is quickly overturned as the gloomy message of the song is substituted by Bøving's voice reassuring the viewer that "there's always hope, but it requires that [X] is willing to go through with dramatic lifestyle changes. It is completely up to herself/himself" (DR, all episodes). The first sentence is repeated in four introductions, the last sentence is voiced in all six. With this repeated call to individual responsibility, agency and change become central components of the programme's genetic articulation. As suggested by the show title, the ability and possibility to change lifestyle and, thus, the course of one's life is continually underscored. Even if the show does not turn to gene therapy or other biotechnological solutions, it does insist on the individual responsibility and agency characteristic of the post-genomic imaginary. Ultimately, Vivi uses the family narrative to raise health concerns and challenge the pathological predictions of her genes. She changes her lifestyle, gives up smoking, and starts exercising. In this way, the show's approach to genetic testing is articulated in a tension between traditional genetic essentialism (cf. genetic knowledge as a verdict) and post-genomic agency (cf. genetic knowledge as a trigger of health improvement). This ambivalence might also explain the programme's appeal: Audiences are offered both a story of dramatic existential crisis and a peek into a potential future of hope and control, where gene tests are used as life-transforming instruments in health management.

Tellable tales of genetic risk

The culture of mediated anticipation affords new documentary formats focused on preemptive action in relation to health and illness. The show belongs to the established metagenre of the dramatised television documentary where participants go through an experimental process organised by the medium itself (and sometimes in collaboration with a set of experts). Ib Bondebjerg (2006, p. 121) states that the "socio-psychological reality experiment" and the "clinical experiment" are two subforms of the genre that come close to the show explored here. The goal of these forms is to showcase participants' affectively authentic responses to the format's often surprising, semi-scientific, and spectacular trials (Bondebjerg, 2006). For the audience, the attraction is the experience of digging deeper into often unknown – here genetic – territories of human existence by

witnessing real people respond to – and potentially being transformed by – the experimental setting. In the case of the 26-year-old participant André, the immediate affective response and the (lack of) transformation plays a specifically prominent role.

André fears that he has inherited the genetic disposition for bipolar disorder from his father (the [im]possibility of testing for genetic predisposition to bipolar disorder made this specific example central to medical professionals' critique of the show). The gene test, as interpreted by Folkersen, clears him of carrying genetic risk factors associated with bipolar disorder. However, the pre-patient identity is already a central part of André's self-understanding and family relations. Before receiving the test results, both his father and his mother admit that they fear and expect that André is becoming mentally ill. André's mother interprets his occasional anger issues in a pathological context. His father, who himself suffers from bipolar disorder, says he sees himself and his illness in his son. According to the father, they both wear their heart on their sleeve, and he interprets André's emotional expressivity and volatility as a symptom of a shared pathology. The mirroring of the father in the son carries with it a particularly heavy legacy, as André's father attempted to burn down the family home and kill himself during one of his depressive episodes. Bøving's recounting of the family history is accompanied by amateur footage of the smoking ruins and breaking newspaper headlines.

As Rose writes, genetic identity is established "within a web of genetic connectedness overlaid upon a web of family bonds and family memories" (Rose, 2006, p. 111–112). The assumed shared genetic risk between father and son works alongside the recounted family history to reinforce the pre-patient identity and the relational understanding of André as already ill. Due to the repeated positioning within family narratives and relations, André's affective reaction when Folkersen presents the test results is intense. He is not able to articulate any meaningful interpretation of the news, even when he is continually asked by the show's experts. For about two minutes (9:40–11:20), the show alternates between clips of André crying and answering "I don't know" in response to the experts' questions, and Folkersen's subsequent interpretation of the situation. Faced with André caught in a grasp of affect, the viewer is left unsettled and confused. Even André's mother is rather perplexed when, later, he tries to tell her the news but once again breaks down in tears. For a moment, the intense affective reaction not only breaks the narrative progress and premise of the show – genetic testing as a positive means of individual health management – it also shows us how André's understanding of himself, his life, and his future suddenly reopens not only to new opportunities but to a new uncertainty: "I expected being told that I had it" (DR, episode 1, 11:20), André confirms when Folkersen asks him. When André learns that he is not genetically predisposed for developing bipolar disorder, the news radically alters his future as well as his present family relations and identity. Even if he still shares exactly fifty percent of his genetic code with his father, the sudden lack of the pathological genetic bond opens a new future, but perhaps also severs the sense of mutual obligations and the caring commitment between father and son (Rose, 2006).

The episode about André, however, also attests to the inevitability of pre-patienthood in the age of personal genomics: There is always something (else) to worry about, some potential pathology lurking in the genetic code. After processing the news regarding bipolar disorder, Bøving reluctantly says, "But André uhmmm..." (DR, episode 1, 12:25). Even if the genetic test cleared him of being at risk of developing the feared mental illness, it reveals that André has a heightened risk of developing type 2 diabetes. At the age of 26, however, the long-term prognosis of developing type 2 diabetes does not seem quite as terrifying to André as developing bipolar disorder like his father. The remainder of the programme develops into a battle between André's lack of motivation to adjust his lifestyle and the recommendations of Bøving, who deems his lack of exercise and his habits of partying and smoking unhealthy. André's reaction to the results of the genetic test corroborates to the importance of time perspectives as well as of family history when dealing with personal genomics. It is primarily the intimately known disorders that terrify the participants. Furthermore, it raises the question of *who* the narrator of the pre-patient illness narrative is.

In André's case, it becomes clear that there are two alternative agendas at stake: the television show's pre-patient narrative and André's personal experience of relief and liberation. Charlotte Bøving has the role of the show's formal narrator – we hear her explanations and reflections in the frequently used voice-over feature. However, André is not a fictional character she can control, and after the initial results are revealed, he shows great resistance to playing the assigned part in the already outlined pre-patient illness narrative. Reflecting on narrative entitlement and tellability, Amy Shuman remarks that "some stories are tellable but only if the teller is willing to live with existing categories for interpreting the experience" (Shuman, 2005, p. 7). When André refuses to take on the role of the pre-patient in relation to type 2 diabetes, he not only challenges Bøving's motivational skills, but the entire tellability of the show's pre-patient narrative. There is, according to the premise of the show, *nothing to tell* if André is not caught up in an individual health project after receiving the results, or, in other words, if a measurable physiological transformation fails to happen.

Hence, the show has a transformative biopolitical agenda, which implies that the participants should follow the normative plot line of personal improvement and transformation measured in biometric charts at the beginning and end of each show. This also makes the show recognisable to an audience accustomed to the metagenres of the dramatised television documentary and reality television. However, as Shuman observes, the narrative patterning of life can be challenged "by the negotiation of which specific experiences get made into stories" (Shuman, 2005, p. 13) and, to André, getting the type 2 diabetes prognosis simply does not count as a tellable event or experience. After a catastrophic visit to the gym, which ends with André vomiting due to the strain of the exercise and a subsequent relapse into old habits, Bøving sends him a scolding video. Here, she remarks: "If you do not pull yourself together, I'm afraid that you will not have made a change

when we see each other again" (DR, episode 1, 31:41). Thus, Bøving sets up an alternative measure of success and parameter for narrative closure: Instead of the knowledge of an anticipated future that has prompted André to participate in the show, the goal is now a well-initiated and, preferably, completed health journey. As such, Bøving repeatedly positions André as a pre-patient – someone about to get ill – to ensure narrative drive and physiological change. However, after learning the result, André rejects this positioning with reference to his own quality of life. It seems that being acquitted of the feared future has left André less worried about prognostics and more open to what might happen in the future. In the final session with the experts, the question of children is brought up again, and André states that starting a family is a newfound possibility for him.

(Non)listening to the yet-to-come

Following Derrida, hauntology as a concept does not only describe a condition of temporal complexity but also an ethics of being open – and even welcoming – to the yet-to-come and unknown future. It is a crucial question how this idea of futural openness corresponds with the desire for knowing and controlling the future expressed in the prognostic and anticipatory logic of genetic testing. Is embarking on radical lifestyle changes to prevent future illness a form of care for and listening to the unknown future? Or is it, rather, an attempt to avoid unpredictability by producing the knowledge that allows the subject to autonomously navigate the future and steer clear of crises? And to what extent does the show "care for" versus position participants as responsible for individually choosing their own good health?

The latter dilemma is played out in the episode about the two brothers, Jakob and Mathias, who are both afraid they have inherited the genetic disposition to develop venous blood clots: a condition which has burdened the life of not only their father but also the previous generations of men in their family. Together, the two brothers face their genetic heritage while their father is consistently present as the parent who feels guilty for passing on bad genes to his sons. The test, however, reveals that only the younger brother carries the gene that produces an increased risk of blood clots. From there, the episode individualises what was until then a collective narrative. Now, only one of the brothers must engage in the systematic lifestyle changes called for by the experts, as a testimony to his willingness to change and take his genetic heritage seriously. The family itself attempts to restore collectivity as they engage in a joint project of exercising and changing their eating habits to take care of the health situation of the family's youngest member.

Following Monica Greco (2019), Jakob is confronted with the paradox of being an object of medical authority (he is told his genes cannot be changed) while also being articulated as an agential subject with the ability to choose health and an obligation to take on the task of reforming himself. His genetic profile is treated as a fact beyond his own control, but his lifestyle is heavily framed as a personal responsibility that he, and to some extent his family, is obliged to take seriously. In accordance with the work of

Cressida Heyes, this shows how contemporary and technologically enabled quests to "cultivate a self is caught up with structures of power that also constrain and manage us" (Heyes, 2020, p. 12). Thus, genetic testing seems to create a hauntological situation in which future illnesses become present to and felt by the participants through risk assessments, but also a situation where the future becomes a target of control through preventive lifestyle interventions in the present. This raises the question of how to grasp the relation between, on the one hand, a hauntological acknowledgement of complex temporalities and health as a distributed phenomenon and, on the other, human attempts to reduce and overcome the temporal insecurities. Should the effort to master future insecurities be understood as a mode of listening to the complex entanglements of past, present, and future or, rather, as a negation of this complexity that reinstates an autonomous subject with the proclaimed ability to shape his biological future?

The critique raised against the documentary by several medical experts in key genetic institutions focuses – perhaps surprisingly – exactly on how genetic testing is used by the medium to narrate the future and the illnesses of specific bodies as overtly transparent, predictable, and knowable, but also on how this produces a situation in which the participants are not taken care of properly (Gerdes et al., 2020). In the newspaper op-ed that motivated the removal of the documentary series, a range of serious problems are identified by the experts. For example, participants are exposed in unethical ways during a vulnerable situation, basic medical and psychological standards for performing genetic tests are not followed, genetic tests are framed as being able to clearly determine the health risks of a healthy person, the genetic profiles of family members are not included when determining health risks, and too many illnesses are included as genetically determined. Thus, the experts argue that the documentary exaggerates the predictive potentials of genetic testing and presents participants with risky and dramatic assessments that are framed as trustworthy peeks into the future. The complexity of genetic entanglements of past, present, and future, as well as the need to be careful about how genetic results are presented to and processed by its receivers, are stressed by the experts. Put more polemically, the op-ed could be said to claim that the documentary series is not hauntological or ethical enough in its approach to the temporal complexities and experiences of prepatienthood enacted by genetic testing but instead it reduces the future to a knowable territory and the present to an arena for processes of self-disciplining.

Hence, genetic testing seemingly has an inherent hauntological potential – it produces vulnerable situations of experiencing, encountering, and feeling the complex entanglements of generations and family ties that connect past, present, and future through genetic heritage. These situations enact "existential limit situations" in the sense that the tested subject always, more or less explicitly, encounters his or her own future mortality through the use of this kind of biometric technology (Lagerkvist, 2017). Here, family histories of illness and suffering and future scenarios of becoming ill overlap and intertwine. But the future is also always unpredictable and open to different interpretations.

Maybe the identified risk will never turn into an actual diagnosis, maybe the test is not totally precise, maybe treatment and forms of action will be able to decrease risks. We suggest that a caring approach to these situations would, therefore, in some sense, need to respect and listen to the complex existential and hauntological experiences of trans-generational entanglements and futural insecurity and unpredictability that is the result of genetic testing.

Following the op-ed mentioned above, one could argue that the documentary instead creates a not-so-caring situation by, for example, reducing complex relational and temporal experiences of pre-patienthood to affective remedies that should motivate lifestyle changes through fear and anxiety. Further, the documentary seems to overemphasise the ability of genetic testing to anticipate and predict the future trajectory of healthy bodies and to turn the existential encounter with serious news of potential illness into a media spectacle. By replacing an interest in spectrality with a focus on the spectacular, care and respect for the vulnerable participant is downplayed in favour of the desire for tellable stories of willed lifestyle transformations and visible bodily change.

In the episode with the brothers, these conflicting modes of caring are played out when they are given their different genetic news. Both the father and the older brother react by stating that they would have preferred the opposite distribution of bad/good news. They believe that Mathias would have been better equipped to tackle the negative risk assessment. Jakob, on the other hand, has an entire life ahead of him and is seriously disturbed by the result in his transformation into adulthood. The facilitating physician views it differently: Because of his young age, Jakob can effectively take control over his body and avoid the lurking dangers. A moment of radical care between family members – in which the youngest member is spontaneously cared for as particularly vulnerable – is in this way transformed into an individualised situation focused primarily on futural control and vitality. As such, a complex existential and intergenerational experience is remoulded into a simple biopolitical task.

Conclusion

As a media text attesting to the contemporary shift of the genetic imaginary, the television series shows how new technologies enable new experiences, genres, and narratives of the states of illness and health. The analysis teaches us at least three things about pre-patienthood as a hauntological experience enacted through gene testing technologies: 1) The haunting state of pre-patienthood is *an existential condition*. We are all genetically entangled with our relatives and, in this way, patients-to-be. Anyone could, therefore, participate in the series, as it does not rely on participants' talent or extraordinary life. 2) Hauntological experiences of pre-patienthood are increasingly connected to *encounters with media and biometric technologies* that have the potential to make genetic heritages visible at all states of life. Through these technologically enabled encounters, the often-

forgotten genetic entanglements that precondition individual lives are made present, visible, and tangible in new ways. 3) These mediated or technologically facilitated situations of haunting entanglements generate various types of response or *modes of listening* that shape encounters with genetic heritage and pre-patienthood. The complexity and unpredictability of genetic entanglements of past, present, and future can be respected, cared for, and listened to – or overlooked, exorcised, and tentatively controlled by, for example, enacting simplistic ideas of individual responsibility for the future vitality of one's body, or by turning existential moments of confusion and transgenerational connection into good media stories.

Derrida uses hauntology as a philosophical concept to contend that we are all always-already haunted by the past and the future in a deconstructive and ethical sense. While this may be true, the analysis has also helped to show that the haunted states and narratives of pre-patienthood are intricately linked to the mediating and prognostic abilities of gene testing technologies. The existential, ethical, and technological aspects of contemporary pre-patienthood are thus deeply entangled: Technologies facilitate existential encounters with the haunting past as well as with possibilities, and demands, for handling and listening to the insecurities of the future. The dependency on economic and scientific capital to access and correctly interpret genetic test results, the case shows, makes considerations of narrative agency, tellability, and care crucial for the mediation of pre-patient illness narratives in the genetic era. For now, the critique put forward by the medical experts seems to have shut down further production of the show. However, genetic testing – in its institutionalised and its commercialised DTC forms – is an inevitable part of managing and navigating health and illness today and in the future. While the national public service station has withdrawn from the field, pre-patient illness narratives of tested individuals are still being told, for example, online. As such, the enduring challenge for media – and everyone else – is to find ways to listen to, narrate, and share these experiences of and encounters with genetic hauntings in a caring and respectful manner. This entails that the desire for spectacular and affectively involving stories of pending illness must be counterbalanced by an awareness of the temporal, ethical, and relational complexities of genetic knowledge production.

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Notes

1 To add nuance, the illness narrative tradition has also noticed that life with an illness can be anticipated – for instance due to family histories of illness (Frank, 1995, p. 54).