6 Sensationalizing Disease: "Living with Progeria: Born Different"

The popular documentary series "Born Different" is produced by Barcroft TV for its *YouTube* channel 'Truly.' This channel is the self-proclaimed "home of amazing true stories—celebrating difference, maintaining a sense of wonder and confronting the extreme" (Truly, "Kanalinfo"). In this function, it offers clips about people with rare illnesses and disabilities and follows their everyday life. Whereas this endeavor certainly contributes to show the diversity of humankind, there is always the bitter after taste of sensationalism within these stories. Are people watching because they want to learn about meaningful lives that are outside of the realm of a supposed norm or is this a modern form of 'freak shows,' exhibiting people for being 'different'? The description of the series "Born Different" suggests the former, as it reads

> Born Different showcases amazing individuals across the globe, who despite serious medical challenges, have risen to take on the world with a bold heart. Our stories follow amazing people as they challenge stereotypes, break-down barriers and battle to prove they have what it takes to succeed. Inspiring, poignant and humbling, each of our characters force you to leave your assumptions at the door. (Truly, "Born Different")

The mission statement of the series thus suggests that it aims at disrupting stereotypes and advocating for meaning in every life. However, the general wording of the statement suggests that, at the very least, there are tendencies to fall into the trap of regarding diverse characters from a normative standpoint. This perspective emphasizes that people who are allegedly 'different' can be happy *although* they are not like everyone else, instead of pointing to meaning in a life without cross referencing a supposed norm. The first indicator for this would be the phrase 'rising to take the world *despite* serious medical challenges.' In that connection Katie Aubrecht, et al. point out that "[d]isability studies scholars highlight how narratives in which individuals overcome the limits of their minds and bodies perpetuate pervasive disability tropes and tired old cultural scripts. The shadow to these heartwarming narratives is that they also individualize experiences of disability, rather than politicizing embodiment (or recognizing its socially mediated nature)" (4). By portraying 'amazing individuals' who 'overcome' the challenges of their disease or disability, "Born Different" can be accused of not contributing to a discourse of collective acceptance but to neoliberal ideas of the high preforming individual. Hence, instead of accepting diversity in all areas of life, including the body, the format suggests—with its title as well—that there is a norm and that only those existing outside of it face the challenge to find meaning and happiness in life.

Claiming a certain norm is criticized by disability studies scholars such as Elizabeth El Refais who argues that "the qualities, states, abilities, and actions of our bodies that we perceive and understand to be 'normal' are largely determined by the values and assumptions that our culture imposes on us" (2). Thus, whatever is considered to be 'normal' is constructed through public discourses and supported by formats such as "Born Different." In other words, by calling the series "Born Different," the runners implicitly define what is normal and what is not. Consequently, the documentary series does what has been criticized by El Refais: it claims that there is a 'norm' with all positive connotations this brings with it and, at the same time, sets everything that is 'different' apart, implying that it is less valuable.

Although "Born Different" self-proclaims to attempt to portray positive images of individuals, the fact that the production continuously points to people's 'difference' establishes the subjects of the documentary as outsiders to society unless they actively work against this exclusion. Applying van Dyk's postcolonial reading of age(ing) would then suggest that the subjects of the documentary also become romanticized 'others.' Not necessarily because the norm longs to be like them in the sense of the physical but because they supposedly transport a positive mindset. Moreover, the title can be read as implicitly reinforcing a neoliberal agenda. The format distinctly deals with people who were *born* 'different,' hinting at genetic disorders or birth defects. The title thus suggests that their 'difference' is not their fault. They were born that way and did not fall sick due to what would be considered harmful lifestyle choices such as smoking or drinking.[1] This goes to show that the mere format discussed in this chapter is everything but unproblematic. These problems of representing 'difference' need to be ever present in thinking about the way these videos frame the people they are portraying.

The episode of "Born Different" subject to this chapter, "Living with Progeria: Born Different," follows five people with progeria in different stages in their life.

---

[1] The stigma of disease and a culture of blaming the people affected has been discussed by Susan Sontag in her book *Illness as Metaphor* in terms of Tuberculosis and Cancer. A similar argument has been made by Paula Treichler in her monograph *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* about HIV/AIDS. Both scholars argue that there are certain diseases that are culturally framed in a way that blames the victims of the disease for contracting it in the first place.

Contradicting popular believe, there are not only children affected by the disease and, as the documentary shows, there are milder forms of it, allowing people to grow much older. As the focus of this study is on children with Hutchinson Gilford progeria syndrome, I will however only discuss the examples of the children with progeria introduced in the first two segments of the program, arguing that Adelia Rose as well as the Michiel and Amber Vandeweert are staged as a romanticized 'other' in terms of their attitude towards life. In that sense, they do not become role models of the aging body but role models in the philosophy of life.

6.1 Adalia Rose: Progeria between Fragility and Empowerment

Adalia Rose has been one of the most prominent public figures with progeria, ever since her mother started posting about her on social media in 2012. Besides being featured in the "Born Different" series, Rose, who passed away in early 2022, managed her own *Facebook* and *Instagram* accounts, as well as a *YouTube* channel with 5,65 Million followers. Having been a public figure since she was six years old, Rose has experienced both: tremendous support from her online community as well as hatred and cyber bullying. Besides derogatory comments underneath her posting, she has been subject to a death hoax in the past (Tomilson). Despite having been through much in relation to the public her love for posting videos and pictures online has not ceased.

In fact, her several accounts can be read as a very public coming-of-age story. Whereas her mother created the first account for the then six-year-old, by 2020 Rose wrote in her *Instagram* bio "I AM 13 now respect me!" (@adalia06).[2] This demand for respect can be read in two different ways which are by no means mutually exclusive. First, she might be demanding respect from her followers, defying cyber bullying. Second, this demand may go out to her parents, asking for the sovereignty over her accounts and therefore over her own story. What this statement definitely shows is that Rose connects respect and, if we stick to the second reading, agency, to institutionalized age. Because she has lived a certain number of years, she is entitled to a higher level of respect. In this instance, she behaves in a way considered typical for a teenager, claiming that she is grown up and mature. Looking at a case that is, from the institutionalized age angle, positioned at a major threshold in life, makes this example, or progeria in general even more fruitful to discuss. We are not only looking at children in an aged body but at 'young' adults who live with a disease and the knowledge that their lives will be significantly cut short while they face the struggle of growing up. What, then, is age and time to these people? And:

---

[2] This statement in Rose's *Instagram* bio is from August 2020. By now, the bio has changed.

Does the aged body influence their behavior and/or the way they perceive their own age(ing) and/or the way it is perceived by others?

In this subchapter I will look at the way Adalia Rose is portrayed within the framework of "Living with Progeria." I will trace the way she is fabricated as a child, teenager, or 'young' adult in mind, versus an elderly person in body. As with the discussion of centenarian narratives, there are a basic questions that can be addressed to all progeria narratives. How are these people portrayed and how do they portray themselves? In other words: how are they fabricated as public figures and/or commodities. In order to understand the processes of fabricating children with progeria, it is crucial to understand how the public interest concerning them is sparked and how they are turned into a phenomenon and spiritual role models geared towards popular interest. In that connection, it is essential to bear the question of agency in mind. Who tells the story and has thus power over the definition of age(ing) in general and progeria in particular? In the case of Adalia Rose, "Living with Progeria" stages her as a fragile figure who sparks pity rather than empowerment. This is particularly done by taking away her own agency and moving it toward her parents who get to tell her story for her. Despite her fight for agency on her social media channels, Rose is mostly portrayed as immature and in need of protection from the outside world. This, in turn, makes the message of the need to fight in order to find meaning in her life even stronger.

6.1.1 Staging Adalia Rose

This episode of "Born Different" introduces Adalia Rose before it plays the intro to the series. As with every new encounter, in a filmed documentary the first impression the audience gets to experience is the outward appearance of the person on screen. This first visual impression may be closer to a real-life encounter, but it also has the power of framing the narrative. In her discussion of Tito Mukhopahyay's *Beyond the Silence,* Mita Banerjee points to a crucial difference between a written text and a video:

> We witness [Mukhopahyay's] body only in writing. Had we looked at the CBS documentary, on the other hand, we would have seen a boy sitting on his bed, with his body spinning for no apparent reason. It would have been at this very moment, I believe, that our gaze would have taken on the parameters of a medical, a diagnostic gaze; we would have looked at the boy's body not as the body of the author who wrote these poems, but as the body of a severely autistic person. (*Medical Humanities* 52)

What Banerjee describes with regard to a representation of the body of an autistic person, can also be argued for children with progeria—or any kind of representation. Because the first impression we get is a visual one, there are immediate questions about Rose's condition and the reason why she looks the way she looks. In a written text, Rose could have acted as a person without the focus being on her condition, in this video, she is immediately established as patient or at least as someone deviating from a cultural norm.

However, the audience does not learn what kind of patient Rose is during the first minutes of the documentary, a suspense that may add to the phenomenon she is portrayed as. In the initial shot of the clip, we see a person with aged skin, hands that show signs of arthritis,[3] and glasses that seem a little too big ("Living with Progeria" 00:05). In the next frame, we learn that this person is also wearing a hearing aid and that her hair is actually a wig (00:09). People who know more about progeria may recognize the beak shaped nose and high pitch voice as typical features of the condition. Furthermore, the fact that Rose is initially shown next to her father shows how small she is. This notion is heightened through recurring close-ups on her feet, showing her very thin legs in oversized socks, looking as if they could break under the slightest pressure (01:47). Her outward appearance indicates fragility and dependence. Although Rose, by definition, does not look 'old' in terms of her entire appearance, her depicted fragility can be connected to expectations of fragility in 'old' age. Because her body shows outward signs of 'old' age when focusing on individual body parts, she is linked to stereotypes of that life stage. On the other hand, her outfit, including pink glasses and lip gloss counter the notion of an 'old' outward age, adding features of a teenager.

In addition to this multilayered first impression in terms of outward age, in this scene Rose's stepfather (from here: father) explains to her where the camera is and where she has to look. This video is from 2019, when Rose had been making videos for social media for several years and is quite possibly not in need of technical assistance when it comes to questions as simple as 'where is the camera?' Rose would also be considered a 'digital native' with regard to her institutionalized age; that is, someone who has grown up with digital technology and intuitively knows how to handle it. This assumption is backed later in the documentary, when she is shown competently filming herself with her phone (04:31). The initial scene of portraying her in need of assistance from her father then, becomes an instance of mansplaining or, in this special case, dadsplaining—an act where a man explains something to a woman that the woman is perfectly aware of herself, or, here, a father, engaging in the same mechanism with his daughter.

Reading the scene against the grain provides yet another perspective connected to the depiction of Rose's outward age. Because of Rose's outward appearance, highly influenced by her skin, one cannot help but notice the parallels between this

---

[3] The condition of arthritis is in medical terms not restricted to the later life. Yet, it is associated with it. Even though there is juvenile arthritis, cultural imaginaries connect the disease in general to the aged body which links the image of Rose's hand directly to 'old' age.

scene, and those of children explaining the world of technology to their parents or grandparents, connecting Rose to 'old' age in yet another way. The initial scene of the documentary thus juggles with the subcategories of age, emphasizing that in the persona of Adelia Rose, they do not align. All these juxtapositions already highlight that Rose is considered 'different,' which is reinforced by a voiceover from her mother, stating "I just told her, like, yeah, you were born different. That's just who you are. And she owns it" (00:10-00:14). After showing the audience that Rose's condition would make her seem not normal, her mother's statement verbally confirms this and provides the transition into the intro of the show. Besides confirming what the video has already visually established, Rose's mother makes one other crucial point: being 'different' is okay, yet, it will always be the focal point of a person's life if they are considered outside of a cultural norm. Much like Macklemore's music video, this documentary sparks phenomenology by showing something that would not be expected. In both cases, extraordinary age becomes a commodity generating public interest through staging 'difference.'

In the subsequent scene, the documentary immediately touches upon questions of dependence and fragility. Rose's mother wipes something from her daughter's eye with a tissue (00:35). This act of care may not be considered age appropriate for a ten-year-old[4] person, who would be considered capable of wiping her own eye. However, this is where illness and impairment come into play. This behavior is portrayed as acceptable and necessary because it is known that Rose is sick. In turn, it also works to underline her illness and stage her as fragile and dependent. Contrastingly, moves like this are largely absent from centenarian narratives. Centenarians, it seems, need to put a lot of effort into proving their ability and independence, whereas the same does not go for Rose.[5] What is established through this scene, then is that through physical limitations, Rose is engaging in age inappropriate behavior—a soon to be teenager would be assumed to not let her mother wipe her eye. This break between expected and actual behavior due to the body increases an image of Rose's general fragility.

Whereas it is certainly a point of critique to deny extraordinarily aged bodies to show signs of fragility in public representations, as often done in centenarian narratives, staging them as overtly fragile is moving toward another extreme. In aging narratives, it seems, and this goes along the lines of Gullette's argument of progress versus decline, there is rarely a middle ground. Although centenarian narratives try to break with the binaries, there is still only a part of the picture

---

[4] At the time the documentary was filmed Rose was 10-11.

[5] Of course, this comparison is a stretch, as I am referring tremendously different institutionalized ages and therefore family structures and systems of care—the mother, as seen in this scene, is supposed to be the caretaker of her child in dominant discourses of Western cultures, no matter how old the child is.

the public gets to see. The same seems to apply to this narrative of Adalia Rose, yet, instead of portraying her as independent and pointing to what she is able to do despite her condition, the documentary portrays her as incredibly dependent, needing help with every move she makes, thus emphasizing her 'difference.'

The assumed physical fragility is supplemented by the portrayal of Rose's speech. For one, Rose's speech acts are often supplemented by subtitles, indicating that, although a native speaker of English, she is unable to articulate herself in a way that is understandable to the audience. Rose has a very high-pitched voice, speaks rather fast, and occasionally mumbles, which makes her harder to be understood. Yet, arguably, subtitles are not necessary to follow her words and other documentaries featuring Rose make do without them. Adding subtitles hence heightens the impression that Rose is not able to articulate herself, making her more fragile. Moreover, the use of subtitles here also justifies the lack of agency: because Rose supposedly has trouble articulating herself, it makes sense that others speak for her. Ultimately, the documentary fails to counter stereotypes here and reinforces that someone whose speech does not conform to a norm is to be given less agency than others. As opposed to Rose,

In addition to the fragility portrayed in connection to Rose's body, the documentary also points to a sense of fragility when it comes to her mind. Her father explains that they "don't put any fear into her or like explain what progeria is or even say the word progeria" (00:40-00:47). While not inducing fear may be a noble attempt, Rose is imagined as too fragile to cope with her condition. Surely, one might argue that Adalia Rose is a child and does not need to be burdened with the result of her condition. However, not talking to her about it takes away her agency to react to the disease and to come to terms with her shortened life span. Rose does not go to school (Tomilson) and thus lives within a bubble created by her parents. Within this bubble, she is protected from the dangers of the outside world, yet, she is unable to act on her own account. In that sense, Rose is portrayed disengaged from society and lacks the agency to tell her own story.

It is important to note that this portrayal of mental fragility is not common in the portrayal of Rose. As I will discuss later in this chapter, in other media sources, she is portrayed as strong and empowered. Other media outlets also show that Rose is part of a progeria clinical trial, which indicates that she must have a basic idea of her condition ("Check Up"). Further, her social media accounts show that she was indeed aware of her condition. According to a *Facebook* post published after her death, she even engaged in the panning of her own funeral (@Adalia Rose). Consulting other sources thus suggests that the fragility portrayed here is a means of "Living with Progeria" to highlight Rose's deviance from a supposed norm, making her case fit the framework of the documentary. At the same time, however, the documentary portrays Rose as being happy within her protective bubble of difference. The ability of being happy despite all the restrictions emphasized here leads to a heightened sense of Rose as a role model when it comes to a positive attitude in life. In the following, I am thus discussing the representations, as shown in the documentary, fully aware that not only Rose but, to some extent, also her parents may be staged through this production. Ultimately, the question hence is to what extent this is even Rose's narrative. How much of the negotiation of the progeria body is actually in accordance with Roses experience (or the experience of her parents)? How much of what we see are interpretations and imaginaries provided by producers (or parents)? The following section of this chapter will explore how the age(ing) body is further framed through the documentary, bearing in mind that Rose herself may not contribute too much to this process.

6.1.2 Negotiating the Progeria Body in Terms of Time

Rose's parents' refusal to mention the word progeria could suggest that they are in denial about her aging body and therefore about her condition in general. Hartung and Kunow explain that "denial frequently takes the form of an internalized strategy of the self, which exiles old age from a meaningful self-conception by a continuous temporal displacement" (16). This form of temporal displacement, that is, the notion of not yet being 'old,' restricts individuals to come to terms with their experience and render it meaningful. While Rose's parents engage in a different form of denial by attempting to ignore an illness, the effect remains the same: by not engaging with progeria in the first place, there is no chance to engage with it in a meaningful way. Denying the condition or 'old' age in general then equals yielding to cultural imaginaries of decline. "Living with Progeria" hence does not contribute to a possible meaningful engagement with disease and rather heightens the sensationalism thereof.

Connected to an imaginary of decline, Rose's condition is staged as a phenomenon of being 'different' by portraying her as fragile, yet happy. However, the documentary does not manage to go beyond reinforcing her 'difference' and thus generates pity for children with progeria. Questions of how to come to terms with a condition that makes aging an illness are only raised implicitly. Referring back to Kübler-Ross, Rose and her family, at least according to this documentary, remain in the denial phase of their coming to terms with progeria and especially with the limited life span connected to it. This presents a stark contrast to what has been discussed in terms of centenarian narratives. Especially Aldéa Pellerin-Cormier and George Dawson seem well aware that their lifetime is almost over, and both seemed to have come to acceptance. Here, the crucial issue of temporality comes into play: Pellerin-Cormier and Dawson did have a long timespan to live and to come to terms with the inevitable end of life. Adalia Rose and her parents did not have this time and quite frankly, acceptance is assumably easier to find after living over 100 years.

Generally, this direct comparison between centenarians and children with progeria with regard to the role of grief presents to be difficult and is to be made with the utmost caution, but it nevertheless points the audience of both narratives to the question of age, illness, and temporality. In that connection Jan Baars explains that "[i]t appears to be impossible to experience 'time' directly, without any culturally mediated constitution of time. Experiencing time always presupposes a culture that has interpreted and organized time in specific ways" ("Concepts of Time" 291). Because a life span is imagined to last a certain time, we perceive people who exceed this time to have been given a gift of more years while those whose life is shortened appear to be robbed. In this case, it may be much easier to accept the end of a life while living on gifted time than it is for someone whose time has been stolen. In that sense, children with progeria are not only 'old before their time,' as Hayley Okines suggests in the title of her (auto)biography, but they are also dying before their time.

The juxtaposition of age subcategories and their connection to age(ing) and time are portrayed within "Living with Progeria" by depicting Rose's eleventh birthday party. The documentary introduces the segment about this day with large lettering on the screen: "Tomorrow is a special day for Adalia. Tomorrow she turns 11" (04:04). Unlike Macklemore's grandmother, Rose's birthday is not considered a special threshold birthday. She turns eleven which is, apart from being the first repdigit number in a human's life, a rather ordinary birthday. However, the documentary turns this birthday into something special as this initial statement only appears roughly twenty seconds after one explaining that "[s]tatistically, most children with progeria don't live past thirteen-years-old" (03:40). On the one hand, this juxtaposition of institutionalized age and life expectancy can be read as yet another form of sensationalism. On the other hand, it creates the notion of limited time and thus emphasizes that life with progeria is an accelerated life. Because Rose has such a limited life span, it is crucial to squeeze as much into this time, as possible. This provides another parallel to Macklemore's grandmother, who claims that 'she wants to do it all.' There, too, is a notion of urgency because if centenarians and children with progeria do not do whatever they want to do now, there might not be another chance.

The emphasis on limited time also raises the question of how a birthday is celebrated when there is the imminent fear of Rose's days being critically numbered. Does each birthday become an achievement like with the centenarians or is the number of years lived less of an accomplishment and more of a threat? The fact that the documentary deals with the birthday in the first place gives it a certain significance. The time for filming was quite possibly chosen purposefully in order to specifically include Rose's birthday. Yet, her birthday is not staged as a special threshold. Rose herself considers it a special day because she is looking forward to all the presents. The day itself seems to be like an ordinary eleventh birthday.

Rose is taken to the mall to eat ice cream with her family and then gets to pick out a wand and a tiara at an accessory shop. She clearly enjoys being the center of attention but there is nothing out of the ordinary in the celebration of that day. Yet, putting the day within the framework of what the audience has learned about progeria, the birthday celebration is imagined to be 'special' nonetheless. If Helen's birthday celebration would then be considered extraordinary due to her institutionalized age, Adalia Rose's party can be read as the same due to her physical age as well as the reduced time and altered temporality of her life.

The sense of altered temporality adds to a depiction of fragility: not only Adalia Rose as a person is fragile but the remaining time of her life is as well. Yet, there are rare moments that can be read as a form of empowerment, which however remains superficial because the lack of knowledge about her condition restricts Rose from the opportunity to cope and overcome. Her narrative thus cannot become a personal illness narrative because she does not get to make sense of her illness in the first place. The following subchapter will trace these rare forms of empowerment and compare Rose's representation in "Living with Progeria: Born Different" to other formats she is presented in.

6.1.3 Traces of Empowerment and the Need for Autonomy

Besides staging Rose as fragile in terms of her body, as well as her ability to cope with her own condition, the documentary shows superficial moments of empowerment. These moments are supplemented and reinforced through other representations of Rose that stage her in a less fragile light. Where is this empowerment then that the description of "Born Different" promises? There is a little bit in statements such as "[t]here is days when she goes 'I wish I had hair, I wish I looked like everybody else' but then she goes and says: 'Who needs hair anyways? I have a bunch of wigs'" (01:18-01:20). This statement goes along the lines of what many disability studies scholars argue: Not being considered to be part of a supposed norm, is not automatically to be regarded as negative. After all, every individual is different and, in Rose's example, having hair does not define a person. She has learned to help herself with various wigs and thus has the advantage of not having to go to the hairdresser in order to change her style. This statement about having hair, which seems to be insignificant at first, is a step towards empowerment. At the same time, this empowerment works through the attempt conforming to a social norm. Rose does not embrace her boldness but wears wigs in order to appear more like any other pre-teen.

It is important to note, that there is an ongoing debate on whether people with illness or disability should rather try to conform to a physical norm or embrace the diversity of their conditions. In the community of people with hearing-impairment, for instance, there is a movement to embrace sign language as an official language and refrain from using Cochlea implants to conform to mainstream society. Amelia Cooper elaborates that for many activists "deafness is not defined by the lack of ability to hear, but rather, by a distinct cultural identity of which they are proud" (470). Whereas there may not be a distinct cultural identity of children with progeria, there certainly is, as I will discuss in the following chapters, a strong sense of community. Whether hair loss would then be regarded a distinct feature of people belonging to this community is debatable. What this approach suggests, however, is that Rose's personal form of empowerment may be criticized as selling out to mainstream society.

Rose's social media presence can certainly be regarded as another form of empowerment. She puts herself out there and shows that she is a happy person, enjoying life and, at the same time, defies derogatory comments about her persona. With her online performance, Rose manages to step out of the isolated 'waiting room' of her 'old' body, at least virtually. Social media is not only a hobby but also serves as a form of reassurance for her, as, apart from a few demeaning comments, public responses are often positive. Her mother explains that "every time she hears those things, it makes her really happy" (05:53-05:56). Rose's mother points to the positive aspects of her daughter's public performances. However, the issue of negative comments is not at all addressed in the documentary. Leaving the negative comments out of the narrative has a twofold effect: first, it makes Rose's public appearance seem much easier than it actually is for her and her family. I would argue that talking about these negative aspects and how Rose deals with them would be a stronger message for her empowerment and strength. Second, leaving out this information makes the audience wonder whether Rose is not receiving any derogatory comments or whether her parents shield her from this, too, increasing the walls of her protective bubble and again shielding Rose from the world. Focusing only on the positive aspects of Rose's social media life implies agency for Rose to some extent. On the other hand, leaving out the negative neglects the chance to portray Rose as a strong person who is able to overcome hardships. Reading against the grain and focusing on the gaps of the narrative thus reinforces a sense of a purposefully staged fragility.

Opposing the representation in "Living with Progeria," there is a KUVE[6] news story, dealing with the issue of demeaning online comments, as it describes how Rose confronts cyber bullies on her page. In this short segment, it is mostly Rose who speaks, not her parents. She explains that "sometimes [my mother] starts crying but I'm like 'you're fine'" ("YouTube Star Bullied" 01:59-02:00). Rose thus indicates that she is the strong one in this situation and by no means in need of protection. Rather, the mother-daughter roles appear reversed with Rose comforting her mother, telling her that everything is going to be fine. Furthermore, she explains

---

[6] KUVE is a virtual news channel, affiliated with ABC, located in Austin, Texas.

that she is focusing on the positive and listens to the people who tell her that her videos make them happy. To the bullies she says, "oh honey, ya basic" (02:50-02:52). Here, she acts quite sassy and ultimately, presents a strong mindset to deal with these issues. This short news report gives the impression of empowerment much stronger than the entire "Living with Progeria" segment on Rose. This intensifies the notion that the documentary deliberately stages her as a fragile person who needs to be protected from her situation.

Contrasting the narrative of the news segment, the documentary leaves negative social media comments out of the picture. As above mentioned, this, in turn, gives the impression that the protective infrastructure surrounding Rose is maintained by keeping these negative reactions from her. The implication of a restricted access to the social media comments are yet another debatable instance of the protective bubble Rose lives in. This very bubble is yet again intensified in another instance, not directly related to social media but to progeria itself:

> **Father:** We don't talk about life expectancy or any possibility of this can happen, that can happen to her, I mean we just live day by day.
> **Mother:** I mean anything could happen to anyone. (03:50-03:55)

On the one hand, this conversation conveys some sort of wisdom: Only because we know that Rose has a shorter life expectancy, there is no reason to worry her with it. After all, she could die in a car accident any day. This statement then becomes a way of empowerment for the parents, a coping mechanism and a strategy to deal with the impending loss they will have to deal with eventually.

On the other Hand, this statement in particular and the entire protective infrastructure built around Rose in general raise question about the ethics of the situation. Is Rose entitled to know about her condition and what it ultimately means for her life? Thinking back to Beauchamp and Childress' principles of biomedical ethics provides a fruitful angle on this situation. One of these four principles[7]—autonomy—makes it rather clear that an action can only be considered as ethically acceptable once the patient can make an informed decision about it. This entails that the patient knows, to their best ability, about their condition and possible causes of action. Another principle would be justice or the demand to provide fairness for patient and society. It remains questionable whether it is fair towards Rose not to keep her informed about her condition. The other two principles non-maleficence (do no harm) and beneficence (do the best possible thing) are even more intangible. Rose's parents are presented as keeping crucial information from

---

[7] These biomedical principles aim to provide guidelines for medical treatment or testing. In Rose's case, there is no instance of treatment directly. Yet, I would argue that these principles are certainly applicable to broader questions of ethics such as, how to deal with a minor who has a terminal illness.

her in order to protect her. They thus try to keep harm from her by preventing her from living a life in fear. However, by taking that away from her, they also take away the possibility to cope with her situation which, I would argue, has the power to do harm, although the attempt is to do good.

Within this maze of ethics and empowerment, age plays a crucial role. Had Rose reached the institutionalized age of 18, her physicians would speak to her directly and there would be no question about how much information she should be given. Furthermore, as will become clear in my discussion of the Vandeweert siblings, young age contributes to the possibility of staging a person as fragile when it comes to the mind. Because Rose is only ten (or eleven) she is considered a child and therefore in need of protection. However, by protecting Rose from knowledge about her disease, she is also denied to contribute to the decision-making concerning her own health. In this very instance she is denied autonomy and agency, which restricts her from being an empowered individual.

The question of medical emancipation in connection to age is not a new one. It has famously been discussed in fiction through the novel *My Sister's Keeper* by Jody Picault, as well as in the movie based on its story. In the novel, thirteen-year-old Anna sues her parents for the rights to her own body, as she frequently had to donate bone marrow and is now required to donate a kidney for her sister who would be dying of leukemia without Anna's donations. The novel discusses the question of who should have agency over a body and how age should not have the power to deny that agency. Although a work of fiction, the novel makes a convincing case for the medical emancipation of minors, as they should have the autonomy to at least weigh into decisions concerning their bodies, as long as they present mature enough to argue on their own behalf. At the same time, there is legislation in the U.S., stating that "[m]inors usually 12 years or older who demonstrate adequate cognitive maturity and capacity to understand the risks, benefits, alternatives, and likely outcomes of medical evaluation and treatment are authorized to provide consent or refuse without parental permission" (Davis and Fang). This "Mature Minor Doctrine" allows people under the institutionalized age of eighteen to make their own medical decisions, as long as there is no guardian present. Ultimately, empowerment in terms of the body comes with either institutionalized age or a sense of maturity.

Comparing the narrative of *My Sister's Keeper* and the legal framework to Adalia Rose's situation implies that although her 'young' institutionalized age is framed as a reason for her lack of knowledge about her condition, other perspectives may suggest that these decisions are up to behavioral age instead. Both the law and the fictional example point to 'maturity' as the significant factors for medical emancipation. Whether Rose can be considered mature may depend on perspective. Yet, it is difficult to judge by watching the documentary, as Rose herself rarely gets to speak. This lack of agency, in turn, points to a lack of maturity that may well be framed by the documentary. Since Rose is depicted lacking maturity, the documentary presents a justification for its representation of Rose as rather fragile than empowered.

As opposed to these recurring notions of fragility, the section on Rose closes with a sequence of short clips already seen in the documentary, showing her smiling and enjoying herself. This sequence is accompanied by upbeat, positive music and her parents explaining

> **Mother:** I could describe Adalia as a wild one
> **Father:** Yes, stubborn, determined
> **Mother:** Driven
> **Father:** Courageous, crazy (07:40-07:55)

The way Rose is described by her parents in this instance goes against a notion of fragility, suggesting that, at the end of the day, it is her body rather than her mind that needs protection. Here, the parents defy the notion of the need of a protective bubble surrounding their child, thereby contradicting the message conveyed by the documentary so far. This brief statement, however, cannot counter the overall impression "Living with Progeria" conveys through its imagery representation: an image of fragility rather than empowerment. However, this last scene underlines the act of overcoming in Roses case. Despite all the alleged hardships portrayed in the documentary, at the end of the day Rose shows resilience.

6.1.4 Extraordinary Age(ing) as 'Different': Fabricating Adalia Rose

The closing remarks of the segment are then given by Rose herself as she explains that she likes dabbing. This last statement goes along the lines of most other speech acts on Rose's end. She is not denied speaking at all but the things she says are not connected to her condition. Rather, she emphasizes her affinities for behaviors that would be connected to 'young' people, such as dabbing (08:06) or unicorns (01:46). Here again Rose goes against being staged as 'different' and presents herself as a 'normal' pre-teen. However, this statement is preceded by another close up on her feet (08:02). The imagery provided by the documentary thus counters Rose's statement, crucially pointing towards the politics of fabrication. Apparently, as a child with progeria, Rose's body needs to be put into the center of attention in order to juxtapose the rather average behavior of an eleven-year-old with an aged body. Rose's parents, on the other hand, emphasize her behavior and, by not uttering the word progeria, appear to disregard the physical realities of their daughter's life. Rose, when she gets to speak—in this documentary, as well as in other sources—seems to be more empowered than "Living with Progeria" would give her credit for.

The Adalia Rose segment of "Living with Progeria" ends abruptly and the audience is left unsure what the message of the recently seen is. We have met an eleven-year-old who likes to be a social media celebrity. It has also become quite clear that she is kept within a protective infrastructure and is not necessarily aware that her condition means that she has a significantly shorter life expectancy than other people. Therefore, it is difficult to trace how Rose copes with her condition or with her accelerated physical aging process. These things become more nuanced in sections on other people presented in this episode of "Living with Progeria," as well as in the following two chapters dealing with Sam Berns and Hailey Okines.

The discussion of Rose's case has however shown the complexity of progeria, especially in a discussion focusing primarily on age. The aging body is in the center through the way the condition is framed but never really in the center of the way Adalia Rose acts or behaves. This then echoes narratives of decline concerning physical and outward age but a sense of progress concerning behavioral and institutionalized age. By depicting Rose between the cultural imaginary of age(ing), her social roles as a daughter and as a social media persona, and the biological implications of her illness, "Living with Progeria" at the very least offers an entry point into the complexities faced when considering progeria in terms of aging studies: for Rose, age itself is both progress and decline, putting her at the very ends of two binary oppositions. The interplay of these binary oppositions within children with progeria will be further discussed throughout the following chapters.

Ultimately, the portrayal of age(ing), as well as that of illness remains very superficial. As Rose does not get to speak about progeria and her parents rather discuss their *not* speaking about it, it is difficult to trace how the family deals with the condition. On the other hand, the excerpts discussed here show that age and illness always play a role in Rose's life. It might actually be one of the strengths of the documentary to not focus on the medical issues that come with progeria. In that sense, when taking away the sensationalism of the documentary, it does not show 'difference' but the ordinary life of an eleven-year-old. Yet, the documentary fails to bring this much more powerful message across: living with a disability precisely does *not* make you 'different.' Instead, it tries very hard to point towards the few impacts the condition has on Rose's everyday life.

6.2 The Siblings with Progeria: Michiel and Amber Vandeweert

The sensationalist tone identified in the section about Adalia Rose remains throughout the duration of the documentary. However, there is a shift in agency that may occur due to the mere factor of institutionalized age: The older the subjects of a segment are, the more they are allowed to tell their own stories. This bluntly shows the ageism that is tied to questions of agency: Not only does a person lose some of their to agency once they get 'old,' but also, they only gain agency from a certain age or, going back to Field's argument, maturity (cf. chapter 4.2.1). This suggests that a person needs to be of a certain institutionalized age in order to adequately speak about their experience and have their voice valued by a larger audience.

In the case of Georeg Dawson, one could have argued that a full-length (auto)biography needs to be written by a good writer and living 100 years does not automatically provide a person with the required skills. In the case of Adalia Rose, this argumentation fails, as this is an eight-minute video clip, in which she could easily have been given more speech time. The following discussion will thus deal with the question of institutionalized age and agency as well as the way twenty-year-old Michiel and twelve-year-old Amber Vandeweert, siblings from Belgium, are presented and present themselves in the second section of "Living with Progeria."[8] The peculiarity about these two cases is introduced in the first seconds of the segment, as Michiel explains "[t]hey say the rate that you could get progeria is one in eight million, so it's pretty rare. We're brother and sister and we both have progeria" (08:13-08:22). That a disease with only about 130 known cases worldwide occurs twice in one family is extremely rare. Here, again, the documentary points toward sensationalism: the producers did not only seek out people with a rare condition, they also found the rare among the rare. In the following, I will briefly outline how Amber and Michiel are staged and fabricated within the documentary and then argue that they, as opposed to Rose, have more voice in their own story which is not only because of their institutionalized age but also because of the portrayal of physical and outward age, as well. Through this portrayal, I argue, the documentary reveals ageist and ableist structures at the same time: agency is not only tied to institutionalized age but also to the physical condition of a body. Lastly, although the issue weaves through my discussion in the entire chapter, I will specifically point to some scenes that explicitly deal with the question of how age, illness, and temporality are discussed within this section of "Living with Progeria."

In this part of the documentary, the outward appearance of the subjects is introduced alongside Michiel's explanation about the odds of having siblings with progeria. Here, not the condition itself but the fact that there are siblings who have it, is the phenomenon of the story which leads to a less sensationalized portrayal of the condition itself. Looking at the siblings side by side (09:07) suggests

---

[8] The claim that agency grows with institutionalized age can not only be seen in the narrative depicting the Vandeweert siblings but also in the last two sections of "Living with Progeria." These two segments follow two adult women having a milder form of a progeria syndrome. They both get to tell their own stories without the predominant interference of parents. However, since this part of my dissertation specifically deals with children with progeria, I will leave the latter two segments out of my discussion.

that maybe Amber and Michiel have a weaker form of progeria as especially Amber's skin looks less wrinkled. This outward appearance might justify the absence of a protective infrastructure, as both Michiel and Amber appear a lot less fragile than Rose or at least the focus is not put on their fragility as much. However, this shows that agency is not solely dependent on institutionalized age, but rather on notions of fragility that are often connected to physical and outward age. Ironically, this goes against concepts of maturity as it puts the focus back on the biological aspects of the human body. This reading would then suggest that only people who have a strong physique are given agency, thus tying into debates about the patriarchy being in place because females are the weaker sex and are thus given less power and agency.[9] Following this line of argument, it is because Amber does not immediately appear as prematurely aged and therefore fragile in terms of her outward appearance, she is given the right to know and speak about her condition. In this instance, the outward age and the presumed physical age that goes along with it become defining of a person's age and allow Amber to speak where Rose's body is considered too fragile.

As mentioned above, it is Michiel who introduces himself and his condition to the audience. This presents a direct break to what we have seen in the Adalia Rose segment before. Michiel is the one telling the story from the very beginning. This may be because he is twenty years old (another rarity, as the life expectancy for children with progeria is about thirteen), and therefore is given the narrative agency of an adult, as opposed to that of a child.[10] This correlation between institutionalized age and agency is reinforced through the representation of Michiel and his sister Amber. Whereas twelve-year-old Amber gets to speak about her condition herself, Michiel gets much more time and thus much more representation within the clip. Amber's introduction is symptomatic for this assumption:

> **Amber:** Hi, I'm Amber, I'm twelve years old.
> **Michiel:** I have progeria and my sister has progeria, we're the siblings with progeria. (08:58-09:10)

It becomes clear that, opposed to Rose, Amber is not kept in the dark about her condition. She knows about progeria and therefore, presumably, also how the illness affects her body. Nonetheless, it is Michiel who speaks about it and who gets

---

[9] In her novel *The Power,* Naomi Alderman describes a world in which females discover the ability to injure an opponent through mere touch. She thus turns around the idea of physical superiority suggesting that patriarchal structures came into being because males tended to be physically stronger than females, giving them more power and agency to shape society.

[10] Michiel can thus also not technically be considered a child with progeria, as this is the frequently used terminology, I will stick to it throughout this study, well aware that 'child,' 'teenager,' or 'adult' are socially constructed concepts of a life-course that I am trying to discuss.

to introduce it for the both of them. In this instance, he speaks for her, confirming that he, as the institutionally older one gets more power over the narrative.[11]

It is crucial to mention that, although they are from and live in Belgium, both Michiel and Amber speak impeccable English, which is inextricably linked to their ability to tell their own story in this setting. One might assume that they have been brought up bilingual, an assumption challenged by the fact that their father's English is not as good as theirs. The audience never gets to hear the mother speak so we do not know whether the unusual language ability stems from her. As the initial assumption of the siblings having been brought up bilingual is countered by the inferior language skills of their father and the lack of any verbal contribution of their mother, one is inclined to wonder how, especially Amber, has managed to learn a second language that well at such a 'young' age. Amber's skills seem remarkable for her 'young' institutionalized age, making her seem much older through her behavioral age, that is, through her capability to converse fluently in a second language. She appears older and somewhat wiser because she has mastered a skill that would not be expected of her, especially with the direct comparison to her father's language skills. Moreover, she speaks much clearer than, for instance Rose does and her speech acts are not supplemented with subtitles. Hence, Amber's ability to fluently articulate herself in a foreign language contributes to her being perceived older through her behavioral age. This assumption of her having a higher institutionalized age through her behavioral age contributes to her being taken 'seriously' and getting to speak for herself, at least to some extent. Consequently, although, institutionally, she is not much older than Rose, her behavioral age seems to become the defining element of Amber's age. Amber and Michiel are thus staged as self-determined human beings through their abilities. In Amber's case this is done by taking the focus away from her institutionalized age by emphasizing her outward age as well as her behavioral age. For Michiel, on the other hand, a shift of focus is not necessary, as he is 'old' enough, yet not too 'old' to be granted agency through the mere number of years he has lived.

Although Amber and Michiel get to introduce their condition to the audience, there are parts of the story told by their father. He elaborates on how Michiel was first diagnosed when he was six-month-old and how he and his wife decided that the chances of having a second child with progeria were low enough for them to try for another child. This instance shows the peculiarity of progeria narratives: The first part of the story, the diagnosis and a lot of the time a first coming to terms with it is not consciously done by the children with progeria themselves. Rather, there are some aspects of a progeria narrative for which parents or doctors are

---

[11] Another reason for the imbalance in narrative agency could be gender. Michiel as a male in a patriarchal society is granted the right to speak, whereas the female remains in the background.

essential because they are the ones remembering and, especially the parents, are the ones having to come to terms with the fact that their believed to be healthy child has a severely life shortening condition.

Danielle Spencer has coined the term "metagnosis" in order to describe a phenomenon that "occurs when one becomes newly aware, in adulthood, of a lifelong 'condition.' In the broader sense it describes any retrospective revelation pertinent to one's identity. In contrast to diagnosis, metagnosis effects a change in the terms of knowledge, such as a shift in our understanding of disease or of identity itself" (3). Considering progeria, the revelation and change in identity does not occur for the children with progeria but the identity of their parents who, up until the point of diagnosis, believed to have a healthy child. With progeria there seems to be an extended metagnosis that is not tied to the experience of the ill person but to the experience of their parents and their entire family. While the sense of revelation and changing identity is recurring throughout all narratives discussed in the following chapters, in case of the Vandeweert siblings, it is especially prominent. While they already knew of progeria as a disease itself, they were fairly certain that their second child could not have the condition.

Besides these general implications on the correlation between age, illness, and agency, the segment on Amber and Michiel provides insight on how age in connection to children with progeria is portrayed and discussed. As mentioned above, there are several instances in which age categories are turned on their head by the narrative of the documentary. This becomes especially obvious in scenes where the camera focuses on the siblings' hands in contrast to modern media devices. In one close up shot Michiel is shown playing videogames, a pastime that is associated with 'young' people. This is intensified in the documentary as the audience hears shooting noises in the background, indicating that he is playing an ego-shooter game, something that many parents and grandparents would wish their offsprings to stay away from. Michiel's hands look aged, as they show visible signs of arthritis and thinning skin, common effects of progeria (08:49-08:51). The focus on the apparently 'old' hand stands in stark contrast to the action of playing video games. The documentary thus disrupts age as a concept by juxtaposing physical and outward 'old' age with behavioral 'young' age.

Similar mechanisms are apparent in a scene, where Amber's hands, showing similar signs of 'old' age, are shown in a close-up frame, typing on her phone. In this image, there is not only the contrast between the appearance of her hands and their use of modern technology but also between Amber's hands and those of her father, visible in the background of the frame. Her father's hands, which are institutionally much older than hers, appear to be younger through the absence of arthritis (09:36). Again, the arthritis struck hand is juxtaposed with modern technology, in this case a smart phone. Ultimately, these two images focus on the siblings' 'difference' again, emphasizing that they are 'young' people in 'old' peoples' bodies. This emphasis is only possible because there are behaviors that are considered age (in)appropriate. The presumed inappropriateness of 'old' people playing video games or texting their friends becomes an ever-present aftertaste with these images, moving the focus away from any portrayal of normalcy. Nonetheless, this focus shows the struggle of determination what age is. Although playing with age categories, narratives of children with progeria seem to defy any norm when it comes to the concept itself.

This challenging of age assumptions is not only done by mere camera shots but rather by the siblings' behavior and their portrayal of their own life. Michiel likes go-carting, an activity, he can only pursue once a month as he explains: "It's quite physical, so, after like fifteen minutes, I get pain in my shoulder or my arms. So, I try to go as much as I can for what's physical possible" (11:56-12:09). Due to his bone structure, it is painful for him to engage in a high impact activity such as go-carting. However, the pleasure prevails, and he accepts the pain that will follow. Consequently, he denies entering a 'waiting room' of 'old' age, merely because his body is aged. Conversely, he does not let his physicality determine the construct of his age or at least works very hard against it. Yet, his physical age is by no means veiled by the narrative. Rather, his body is put into the center of attention.

Amber takes a different approach to her hobby, dancing. She explains: "I like to dance but I can't do it in dance classes because then my hips and my knees hurt" (12:53-13:00). As opposed to her brother, Amber listens to her pain and accepts the restrictions her body gives her. Instead of participating in dance classes, she dances at home. Ultimately, of course the way to deal with the function of the body is up to the individual. Showing both approaches indicates that there is a variety of ways to handle physical restrictions and that physical 'old' age does not lead to progress and decline only. Having these two approaches presented parallel to each other signifies a grey area of possibility and individual choice that goes beyond most portrayals of the normative 'old' body. Both, Michiel and Amber, show, that they are not willing to stop engaging in their hobbies entirely, no matter the restrictions their bodies give them. Here, the documentary reinforces gender stereotypes: By showing this stark difference, it suggests that Michiel is the tougher of the two, because he is ignoring the restrictions of his body. Amber, on the other hand, is portrayed as weaker, as she does not go to dance classes at all. There seems to be a hierarchy that includes gender, fragility, and institutionalized age that all tie into the way a person is perceived and how much agency they are given.

Although Amber does not take dance classes, she is by no means disengaged from society. Rather, she is shown out and about with Michiel and his friends in a bowling alley. However, again, we see Michiel's friends and his social life with his sister tagging along. The only indication the audience gets of her having social contacts is her texting. Nonetheless, she is depicted as outside the home and engaging in social activity. In the relationship to his friends, the gravity with which progeria affects Michiel's life is shown, namely: it does not do so, at all. He says about his friends that "[t]hey don't see the progeria part of me. They see me and my personality" (13:26-13:32). Hence, for Michiel and his friends progeria is not a defining trait of Michiels persona at all. Here, the importance of perspective becomes obvious again. Amber, Michiel, and their friends have a different notion of progeria than is suggested by the images provided throughout the documentary. For them, their bodily restrictions are a challenge but are not defining their lives. Their own identity is thus very much informed by sameness to peers instead of 'difference.' Furthermore, this shows that for Michiel and sometimes also Amber, their body has no power in defining their age. For them it is their hobbies, personalities, and friends that have the power to determine their life stage.

But what about the one thing that is inextricably linked to their age and their bodies: their life expectancy? They explain:

> **Michiel**: The live expectancy is twelve years old, I'm twenty so I'm eight years past that. That's not something that's in my mind anymore.
> **Amber:** I'm not really thinking about it because I know Michiel is pretty good and I'm pretty good also.
> **Michiel**: We are taking medicines from America. They say the life expectancy is two years extra on the normal age, so that's a lot for someone with progeria. (10:43-11:19)

Being eight years past the life expectancy is a significant amount of time, Michiel was given on top of what he and his family thought possible. His statement about the drug trial[12] reinforces this notion: He considers two years as a lot of time from the perspective of a progeria patient, as it increases the expected life span by more than 15%. The percentage equivalent to that for the average life expectancy in the United States would be roughly twelve years which appears to be a significant amount. Thus, as the centenarians discussed in the previous part, Michiel appears somewhat content with his life span. He has come, in Kübler-Ross' terms, to acceptance. This, however, may only be possible because he exceeded his expected life span by eight years. Although Michiel has to accept the fact that he will be dying before his time, compared to his friends, given his initial life expectancy with progeria, he got the gift of extra years.

Consequently, lifetime is not necessarily measured in time itself but in expected time. For someone who has been led to believe to die at the age of thirteen, living to fourteen is a gift. To someone who expected to live to seventy, dying at fifty appears unfair. Implicitly this reading points to the privilege of age(ing). This notion is intensified through implications of the aged body within the documentary: although his body shows signs of aging, Michiel is happy about every year he gets to experience. This, in turn suggests that not appreciating life in 'old' age stems from

---

[12] The progeria drug trial will be discussed in detail in the next chapter.

the ableist and privileged, assumption that a body needs to be perfect in order to be worth living in. Progeria narratives then serve as a reminder that life can be meaningful despite a body that would not be considered perfect by a social norm.

In contrast to the assumption that life is only worth living with a perfect physique, Michiel has a different take on prolonging his life: “The oldest child with progeria ever was 26, I’m gonna try and beat that record” (14:45-14:48). He ties into the disruption of the fear of later life, induced by a fear of bodily decline and the competition to get older and older. The correlation between this statement and longevity then shows the irony of late life, connected to the centenarian paradox. Although people generally are afraid of decline, there is also a fascination for extreme longevity. Michiel for progeria then becomes what centenarians are to people without an aging disorder: a role model of aging.

This discussion of Amber and Michiel has shown a different approach to a progeria narrative, providing the perspectives of children with progeria more prominently than that of the parents. It has however also shown that children with progeria have to deal with both ableist and ageist assumptions. Ultimately, the self-perception of Amber and Michiel makes a strong case for the suggestion that physical age should not have the power to determine the way age is perceived or what lives are deemed worth living. Crucially, by showing their meaningful lives with aged bodies, their narratives can be read as a critique of those who fear ‘old’ age because they fear the loss of physical abilities. While the images provided by the documentary “Living with Progeria” oftentimes emphasize the sensationalism of the disease, Michel and Amber’s speech acts counter this notion, presenting their lives not as ‘different’ but as ordinary.

6.3 “Living with Progeria”: Illness as Phenomenon

Although the portrayals of Adalia Rose and the Vandeweert siblings differ in many ways, they share the commonality of staging a phenomenon. In both cases the documentary plays with the juxtaposition of age categories not necessarily in order to allow for a nuanced discussion of the aging process but in order to stage ‘difference.’ The juxtaposed age categories suggest that physical age is not always the determining factor of a person’s age or a person’s life. Analogue to a successful aging paradigm, this documentary fabricates a phenomenon that could be termed ‘successful impairment,’ depicting those people who have managed to cope, stay positive, and make the most of their lives, implying at the same time, that if a child with progeria is not constantly positive, they have failed at life in general.

The documentary depicts the ‘difference’ of progeria as one and the same, taking away some of the individuality of the people depicted. For all the people featured, the main problem they have to face in life is their condition, making them, as the documentary suggests 'different' from normative society, but the same amongst each other. In that sense, the documentary's portrayal of 'difference' is again closely connected to the concept of the romanticized 'other' that is strange but admirable. Ultimately, the documentary's portrayal of age as an illness is connected to Katie Aubrecht et al.'s argument concerning the depiction of a person with a disability or an illness who thrives against all odds: this portrayal feeds cultural tropes of the normal being easy and worthy of meaning whereas any deviation from that norm requires an individual's personal strength to fight for this meaning.

Despite the portrayal of a positive attitude towards life in general, the depictions of Adalia Rose and the Vandeweert siblings differ greatly in other aspects. While Rose is depicted as fragile, disengaged, and without agency, Michiel and Amber Vandeweert are presented as strong, sophisticated, and part of society. Nonetheless, neither of the portrayals appear negative. Rather, they emphasize different aspects of living with progeria, thereby suggesting that the fabrication of children with progeria focuses on a positive attitude towards life more than anything. While the cultural imaginary thus shares several commonalties, the social roles presented are diverse and more or less portrayed as influenced by the biological aspects of aging. While the body in Adalia Rose's case is presented as the restricting factor for social participation, the comparison of Michiel and Amber implies that the range of influence biological realities of the aging body have on a person's life is up to the individual.

In all cases, the children coping with the restrictions of their bodies are depicted as inspiring and amazing human beings, able to overcome the implied challenges life has presented them with. This depiction of awe is thus similar to the fascination brought toward centenarians. However, for centenarians, the awe is directed toward the fact that they seem so good at aging that it does not seem to affect them much. The awe for children with progeria, on the other hand, is directed towards their coping with the fact that they are aging very fast, thus emphasizing their emotional strength.