9 Progeria Narratives at the intersection of Age(ing) and Illness

By discussing the premature aging disorder progeria in relation to cultural constructs of 'old' and extraordinary 'old' age within the previous three chapters, I have shown that there are various ways to approach the process of aging through these extraordinary narratives. I have established how a cultural imaginary of progeria is formed through these narratives and how it is negotiated by them. All the narratives discussed here present a process of aging that is made visible through the juxtaposition of age categories. While there are many common aspects in the way these narratives frame children with progeria—for instance the focus on meaning, happiness, and hope, as well as coming to terms with the disease itself and the strive for a cure—the various narratives have provided a variety of nuances in depicting living with progeria.

While Adalia Rose in "Born Different: Living with Progeria" is presented as fragile and therefore very much determined by her illness and her aged body, the Vandeweert siblings in the same documentary are shown as overcoming their condition through their actions. In both cases, the children are presented as 'different' from a supposed norm and are singled out. Here, progeria as a condition is not presented as an illness or even in its connection to age(ing) but rather as a phenomenon. In *Life According to Sam* progeria and its medical implications are put into the center of the narrative, negotiating the way the physical influences the social. The negotiation of Sam Berns' identity as a teenager, a student, and a patient reveals how any experience is more dependent on a social and cultural context than it is on biological realities of the body. By focusing on the clinical trial for a progeria treatment, the documentary focuses on the biological realms of the aging body and the progeria body and on the connections between them. In Hayley Okines' narrative *Old Before My Time*, the focus is more on the social structures that go along with the condition. While in this full length (auto)biography the references to normative age(ing) are most frequent, the book itself implicitly and constantly questions this connection through the focus on Hayley's behavior.

Especially the latter two narratives suggest that the perspectives on progeria differ between children with progeria and their parents and caretakers, suggest-ing that the explicit connection between progeria and age(ing) is largely part of a cultural imaginary induced by the outside. This imaginary is reinforced through biological similarities between the progeria body and the aging body, putting the biology of the condition into the center of attention. This is not only done through references to 'old' age within the narratives but by biological and medical research and, ultimately, the PRF itself. Reading these stories through the perspectives of the children with progeria, however, suggests that public discourses overly emphasize the connection to the normative aging process.

Although children with progeria are fabricated into tiny 'old' people in public imaginary, which is often reinforced through the narratives at hand, comparing the condition to narratives of age(ing) only works out in parts. While it is certainly fruitful to address the juxtaposition of age categories and questions of care to encourage an alternative perspective on the 'normal' aging process, these narratives are to be understood primarily as illness narratives and only secondly as age(ing) narratives. The age(ing) body narrative is perpetuated especially through medicalization and therefore as an attempt to fund research. Every other aspect of the progeria experience is tremendously different to 'old' age. Thus, the self-identification of children with progeria happens not in terms of 'old' age and not even in terms of illness but rather in terms of what makes them the same as everyone else instead of what sets them apart. While public discourses attempt to stage these children as phenomena and romanticize them as a form of 'other,' the children discussed within the previous chapters do not envision themselves within these categories. In that sense, it can be argued that because they have been 'aged by culture' differently, their perspective on age(ing) and illness differs from the norm. Their social roles are ultimately not affected by progeria itself but by the infrastructure surrounding the disease. Sam Berns is not isolated because of his body per se but because he is put into a hospital that focuses solely on his body and therefore on what is 'wrong' with him. Contrastingly, the narrative parts that focus on the children's roles in every-day life encourage an imaginary that goes beyond this narrow focus and looks at life as a whole.

What this discussion consequently shows is that even when the body ages prematurely, as long as institutionalized and behavioral age are categorized as 'young,' the body is framed differently from the body of 'old' people. Although aging, illness, and disability thus seem to go together in public discourse, the analysis of progeria narratives shows that the framework surrounding the body and the cultural imaginaries attached to it change throughout the life-course. In progeria narratives it becomes abundantly clear that although institutionalized age is the most arbitrary of all age categories and scholars have been calling for distance from the myth of the objectivity of chronology, in public imaginary, it is not the biological that determines age per se. It appears to be the arbitrary number of years a person has lived with all its implications of maturity and participation. In addition to institutionalized age, it seems that other categories of difference, like gender, for example, define the social roles of an individual more than anything.

While progeria narratives are not solely narratives of age(ing), reading them still provides suggestions on how to cope with an aged body, especially when it comes to questions of care: Care in progeria narratives is not depicted as a lonely effort but as a network of public, private, and institutional means in order to support not only the children with progeria but their caretakers as well. As the audiences of the narratives learn about a wholistic approach to care, there is still the idolization of individuals like Leslie Gordon or Kerry Okines who take the lead. Yet, they are also depicted as vulnerable and in need of assistance themselves. Nonetheless, while making suggestions about a network of caretaking that would be beneficial for elder care as well, the narratives all focus on the mother figure as the hero who makes care possible. Reversely, in ‘old’ age it is the absence of a mother figure that makes care a difficult question.

As illness narratives, the representations discussed here focus on questions of diagnosis, medical care, and identity in light of a terminal disease. In that sense, ‘old’ age in these narratives becomes an illness and we are forced to look at the two dimensions alongside each other. While often not directly connected to age(ing), many issues raised within progeria narratives appear to make implications about the age(ing) discourse. Discussing progeria offers a perspective on the aging process while avoiding the pitfall of the successful aging paradigm, yet, the narratives discussed here could be accused of promoting a successful impairment paradigm. All of them, in one way or another, present an emphasis on what the children are able to do, at the same time elevating their own experience against those whose bodies are even more outside a supposed cultural norm. Thus, while the discourse does not primarily focus on the aging process, there are similar narrative structures at hand that also echo neoliberal notions of Western societies. At the same time, progeria narratives to some extent break with the binaries of age(ing) as they present both: progress and decline, ‘old’ and ‘young,’ and therefore show that life is never just black or white but a complex spectrum of different shades of grey.

Reading progeria narratives through the lens of age and disability studies presents to be fruitful in two main ways: First, age(ing) becomes visible through its denaturalization. Consequently, this shows how different subcategories of age(ing) interact with one another and what social, cultural, and biological mechanisms are in place in order to give one or the other the defining power over a person’s age. Second, this extraordinary form of age(ing) works to disrupt normative assumptions about processes that influence human life in terms of age(ing). This disruption, in turn, can be traced back to a normative aging process and serves as a point of inquiry as to why ‘old’ people are imagined in one way or the other by public discourses. Ultimately, the narratives provided here may even lead to a more well-rounded understanding of human age(ing) that goes beyond the imaginary of the life-course as defined by binary structures.

Children with progeria are fabricated at the intersection of illness and age(ing). They are fabricated into a cultural product that inspires not only awe but also pity. They are not paragons of aging but of positive thinking and hope. They do become a commodity, but that process is beneficial to themselves as well. As they are 'marketable,' funding for progeria research increases and it becomes more likely that one day there will be a cure. This commodification only works by constantly referencing the 'normal' aging process and by indicating that investing in these children is an investment in one's own longevity.