

## 10 Conclusion

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The human body, as Nancy Scheper-Hughes and Margaret Lock argue, can be understood as being both “naturally and culturally produced and as securely anchored in a particular historical moment” (7). The body itself, its aging process, and possible diseases or disabilities, as argued throughout this study, are a product of natural or biological realities, cultural imaginaries, social roles, and the implications that go along with them. In order to make sense of the body, it is crucial to not only understand its biology but also its culture, as well as the societal context the body exists in. In that connection the body is negotiated through narrative and thereby becomes a cultural construct.

Arguing that the genre of illness narratives did not occur until the second half of the 20<sup>th</sup> century and then having been majorly influenced by the HIV/AIDS pandemic of the late 20<sup>th</sup> century, Ann Jurecic explains that

[i]t was preceded and accompanied by the emergence of a narrative form not available during the 1918 flu pandemic that has at its center personal accounts of illness and dying. As literary production about AIDS waned, however, the volume of autobiographical writing about illness and disability continued to grow, surpassing the rate of production of AIDS memoirs. Indeed, by the late twentieth century, illness and disability narratives were established as literary genres. (2)

The narrative tools to write an individual story that is the imperfect account of a very personal experience, is a postmodern phenomenon.<sup>1</sup> By shedding the mod-

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1 Jurecic also names other reasons for the lack of narratives about the Spanish Flu. Most importantly, she points to historical reasons: World War One was too prominent in the newspapers for the pandemic to make the front pages. Moreover, governments tended to the war rather than worrying about the spread of the disease. As there was a lack of news coverage, the public was not necessarily too aware of the magnitude of what was happening. Countering Jurecic's point, I would argue that with the HIV/AIDS pandemic as well, there was a lack of coverage and governmental support. Not for nothing did HIV/AIDS activists have to come up with the slogan “silence = death.” Consequently, although there are of course historical factors to bear in mind, I would argue that these are not the main factors in changing the way narratives of illness evolved.

ernist façade of performed perfection, people began to express the imperfection of life and, connected to that, the struggles that illness may bring with it. The focus of illness narratives, or personal accounts in general, would then be on the individuality of the author and the knowledge that every human experience is different. The narratives discussed in this book tie into that logic. Everyone can present their own personal narrative, not only of illness but—with regard to this book—of extraordinary aging as well. However, as the analysis of narratives of extraordinary age has shown, in both—accounts of centenarians and children with progeria—the narratives conform to certain overarching frameworks. They tell, I argued, to a wide extent the story that the audience wants to hear. Instead of seeing centenarians in a nursing home, who speak about loneliness and loss, society asks for stories of ‘success’ which includes being happy and independent. Likewise, stories of children with progeria focus on the art of thinking positive in life and, again, on the success of living this positivity. Thereby, these narratives gloss over the imperfections that are inherent to every life. Ultimately, it seems as if extraordinary aging takes away some of the individuality granted by the era of postmodernism and goes back to a modernist mask fashioned by public expectations. What these narratives mostly provide, then, are archetypical images of centenarians and children with progeria that show the audience the ‘right’ way to be exceptional. Being outside of the norm seems to be socially acceptable, as long as an individual sticks to the rules of their extraordinary category.

While both sets of narratives discussed connect back to a normative aging process and present similarities in terms of biology, the cultural imaginaries of centenarians and children with progeria differ greatly. Although media representations and scientific research draw a connection between the two phenomena, my elaborations here have shown that, despite the notion of the extraordinary, the similarities are limited. Rather, the way these individuals’ ages are negotiated is crucially different.

Narratives of centenarians, or extraordinary long lives, depict extreme longevity as an achievement which is only reached if aging is enacted in the ‘right’ manner. That is, fabricated centenarianism is tied to general health and physical, as well as mental ability. Being a centenarian becomes its own social role, set apart from ‘old’ age by means of establishing centenarians as a desirable other ‘other’ who have overcome the hardships of late life. This explains why Helen in Macklemore’s music video for the song “Glorious” is ready to welcome this new life stage with a behavior that would be deemed age inappropriate if she was not a centenarian. Her narrative clearly sets her apart as special while, at the same time, not denying her outward or physical age. Similar mechanisms are found within “A Sunday at 105.” Aldéa Pellerin-Cormier is depicted in a more subtle, less sensationalized way, yet also at the intersection of the success inherent to centenarianism and the restrictions of her physical age. Interestingly, in her

case the images of the documentary and her own elaborations on her life differ greatly, the former presenting centenarianism very much as a continuation of being 'old' rather than as a new life stage. These discussions are taken up in George Dawson's *Life is So Good!* where extraordinary 'old' age is on the one hand portrayed as the result of a life well lived but, on the other hand, as a mere coincidence. In all three narratives discussed it is rarely anything other than their status as a centenarian that defines their age. Institutionalized age as a focal point is then the driving force behind their depiction. Dawson, although he is going back to school would not be considered a child, Helen, although she sings karaoke is not considered a 'young' adult. Yet, it becomes clear that public discourses surrounding centenarians took up on the way centenarianism is believed to deviate from 'old' age and established a new age category: Because of their institutionalized age, age inappropriate behavior and an aged body become socially acceptable without centenarians being considered disengaged from society. Hence, by fabricating centenarians in connection to the number 100, the publishing mechanisms as well as the narratives themselves become institutions that then define institutionalized age.

Consequently, while the individual narratives can be read as going beyond a successful aging paradigm, the genre of centenarian narratives as a whole is situated right in the middle of it. The people presented show that the imaginary of the centenarian only works if solely those who are able bodied and able minded enough are depicted. Through the absence of disease and disability, these narratives reinforce successful aging through the backdoor: Those who do not fit the cultural image of a more or less physically and economically independent person are not covered in public discourses. Through their absence, they are considered a failure as opposed to the centenarians' success. Moreover, presenting centenarians as 'paragons of positive aging' (cf. Robine and Vaupel), stretches the concept of successful aging, suggesting that only those who live to 100 and conform to the cultural imaginary of centenarianism can be deemed truly successful in aging. The genre can thus be accused of not only reinforcing the paradigm but also setting the bars for what is considered successful aging higher. Furthermore, through the emphasis on behavior, weaving through the accounts discussed, centenarians are portrayed as constantly progressing, diminishing a sense of decline. This sense of progress is also achieved through an emphasis on the future and the possibility on further development. While these mechanisms can be read as attempts to portray meaningful lives and eradicate the binaries of the life-course, by mostly neglecting decline the narratives often conform to the notion that a life has to be either-or: progressing or declining.

Nonetheless, centenarians are not portrayed as ageless, as there is a constant emphasis on their institutionalized age and minor physical signs of 'old' age. With high 'success' at institutionalized aging, the physical performance needed in order

to be considered a successful ager is lowered. Discussing centenarian narratives with regard to successful aging hence shows that success may be tied to individual subcategories of age. At the same time, in order to be still regarded as successful, one cannot be deemed a failure in any of the subcategories. That is, the institutionalized age of 100 may offer the possibility to portray an individual needing a walker as 'successful' at aging; if this individual needed a wheelchair, however, the institutionalized age may not compensate for the physical impairment.

Besides the complexities of age as a social, cultural, and biological construct, the fabrication of centenarians shows that the much-discussed construct of successful aging is in itself made up of many complex mechanisms. These mechanisms are influenced by different age categories, as well as the perspective of the onlooker. The tendency of the centenarians presented to withdraw themselves from the label of being successful shows that this is very much an evaluation from the outside. Extraordinary 'old' people, on the other hand appear to navigate their centenarianness in terms of a continuum, not rating any life stage as more valuable than the other.

The progeria narratives discussed in the third part of this study, on the other hand, show an even greater disruption of age as a normative category. Age becomes visible through the juxtaposition of its subcategories, contrasting the aged body and outward age to 'young' behavioral and institutionalized age. Although children with progeria are often marketed as 'young' people in 'old' people's bodies, their self-definition does not work along the lines of age(ing). Like the centenarians discussed in the second part of this book, children with progeria are hence fabricated in a way that does not align with their self-perception. While the children themselves negotiate their lives in terms of their behavioral and institutionalized age, the focus on the body is determined by the middle-aged people surrounding them. Here, it becomes clear that the people who have already been aged by normative cultural imaginaries need the concept of age as a point of reference in order to make sense of progeria. Children with progeria, in contrast, have only experienced their extraordinary form of aging which, to them, is completely ordinary.

This power of definition over her own condition is largely taken from Adalia Rose who, in the documentary "Living with Progeria: Born Different" appears as fragile and lacks agency. Therefore, the documentary defines her very much through her body and portrays her as disengaged from society. Rose is the individual who is most depicted in light of stereotypes of 'old' age, although her own behavior counters those stereotypes. The same documentary presents the Vandeweert siblings as more engaged and given more agency. This shows how agency is linked to a sense of maturity and, ultimately, to institutionalized age. In both narratives the children with progeria are sensationalized and portrayed as 'other' to a supposed norm. As opposed to this, Sam Berns points to his sameness, indicating that the way his condition and therefore his physique is framed, largely

depends on the social situation he finds himself in. When he is not forced into the role of a patient by being in a hospital, he emphasizes his normality, thereby setting himself apart from the 'old' age science and medicine associate his body with. *Life According to Sam* does not only provide a counter narrative to imaginaries of illness as difference, but it also negotiates medical practice and biology through the depiction of the progeria drug trial. This trial indicates a sense of community amongst children with progeria and their families. A sense of community is taken up in *Old Before My Time: Hayley Okines' Life with Progeria*. By using intertextual references to other progeria narratives, as well as stressing a network of care and mutual assistance, progeria here is presented as a communal issue not only in a medical but also in a social sense. Thereby, there is a notion of individuality within a community, countering imaginaries of children with progeria as 'different' altogether.

Progeria in general is then not solely tied to the biology of aging but to the social roles of a person. Physical age, although often put into the center of the narratives, cannot become the defining aspect of these individuals' ages because they are considered children due to their behavior and their social roles. This is also related to institutionalized age as the defining power behind social roles: Because their institutionalized age informs their social role as children, their physical age only matters in connection to their occasionally being framed as patients. Nevertheless, the connection between progeria and the aging body is frequently specifically mentioned throughout the narratives, thereby reinforcing the connection between the 'old' body and being a patient. This emphasis often stems not from the children themselves, who seem to define their age without taking the aged body into account. Rather, these comments are made by parents or physicians who connect progeria to a normative aging process. In this instance, children with progeria are fabricated as prematurely aged by their surroundings. This oversimplified fabrication serves the promotion of progeria research and, ultimately, the endeavor to find a cure. Consequently, children with progeria are not only fabricated for a purpose, they are fabricated for a purpose that, in turn, will serve them by promising a cure for their disease. The dualism of focusing on the aged body on the one hand and the 'young' mind on the other at times challenges binary structures of age(ing), showing that an 'old' body does not inevitably lead to social disengagement.

Despite telling the story of an accelerated aging process, progeria narratives are illness narratives, tracing the way individuals deal with the proceedings of a diagnosis and the struggle to come to terms with the disease itself as well as its implications for the life-course. In terms of progeria this means, coming to terms with a limited life-expectancy and the knowledge that there is not yet a cure for the condition. The narratives discussed in this study have pointed to the necessity of community in order to cope with the illness. This communal sense may be achieved through social contacts and friendships in general but also through infrastructures

of support from other people and families dealing with the condition, as well as a network of care. In terms of illness narratives, there is again a break between the perspective of the children with progeria presented and other, middle-aged voices within their stories. While the children themselves do not know anything but life with progeria, their parents experience a break in familial identity when they learn about their children's condition. Progeria narratives are thus very much family narratives, as the parents are always involved in the process of grappling with the condition.

By shifting the focus away from the body in many instances and emphasizing processes of overcoming, progeria narratives may also be read as establishing a successful impairment paradigm. Sam Berns, for instance, stresses the need to focus on the things one is able to do, despite personal restrictions. This mindset—which is prevalent in the other progeria narratives discussed as well—can be regarded as a form of empowerment. Yet, looking at the corpus of narratives provided, it again becomes clear, that only those children with progeria are represented who are able to do a lot. While Kerry Okines points to children with progeria needing wheelchairs, none of the protagonists of the narratives presented fall into that category. Similar to centenarian narratives, looking at the people who are represented and those who are not, makes suggestions how to live with impairment the presumably 'right' way. This performance of successful impairment is product of and motor for public ableism at the same time. Because an ableist society needs to be invited to support the endeavor to prolong these children's lives, they need to be portrayed in a way that emphasizes their sameness and therefore their physical ability to engage in all kinds of activities. At the same time, neglecting more diverse narratives of finding meaning within types of physical impairment that are met with stronger stigmata—like being in a wheelchair—reinforces this stigmatization through the absence of its representations.

While centenarian narratives—more or less successfully—try to overcome binaries of aging by showing extraordinarily 'old' individuals and their meaningful lives, thus at least questioning narratives of progress versus decline, progeria narratives blur these binaries by depicting individuals that defy any aging norm. This defiance suggests that everybody is 'born different' and there is not one better way of existing than another. In that sense, although a notion of wisdom is often assigned to centenarians, there are also crucial messages within the narratives of children with progeria. They do not only provide a lens on the aging process that forces the audience to see beyond the naturalized state of the category, they also provide alternative approaches to late life in general, as they negotiate an aged body and the necessity of care without the otherwise ever present notions of ageism. Although these ideas of caretaking follow gender stereotypes of the female caretaker, they also present the necessity of a network and redefine derogatory imaginaries of institutionalized care.

Although this study has set out as an attempt to compare and contrast extraordinary forms of aging, the discussion of both centenarian narratives and narratives of children with progeria has shown that despite their physical age, these two deviations from a supposed age(ing) norm do not share many commonalities. What the comparison emphasizes, however, is that the aged body is framed tremendously different in different circumstances. Although, in terms of biology, centenarians and children with progeria have much in common, they are understood differently due to the vast disparity in their institutionalized ages and the attached social roles. Thus, while children with progeria live extraordinary short lives, centenarians look back on many more years which provides a contrasting framework of temporalities. Interestingly, however, coming to terms with death and dying seems to be an issue in both sets of narratives and is addressed in a similar manner. Both, centenarians and children with progeria, seem content with the limited time they have left. Of course, in progeria narratives, there is the ever-present hope to find a cure but generally, the children presented seem to have arrived at the stage of acceptance when it comes to their limited life span. However, the clinical trials and the experimental treatment spark a race for longevity amongst children with progeria themselves. While it is clear that they will not live to 100, they still aim to outlive the projected life expectancy and, in Michiel Vandeweert's case, hope to become the longest living person with progeria. Both forms of extraordinary age(ing) hence show that it seems to be an integral human desire to live longer than the average. The principles of a meritocratic society are transferred to the aging process, suggesting that the first step towards being considered successful at aging is to live longer than expected.

Both the experience of an extraordinary long life-course as well as the premature aging disease invite for distinct perspectives on the aging process. This connects to the different presentations of the aging body in terms of disease or the absence of it. While centenarians are portrayed as extraordinarily healthy (for their age), children with progeria are extraordinarily ill. Ultimately, these depictions lead to the imaginary of the centenarian as role model and the child with progeria as someone in need of help. Helping children with progeria as well as learning from centenarians, however, serves the same purpose: finding ways to live as long and as healthy as possible. Although the two sets of narratives thus start out at two opposing ends of an age(ing) spectrum, they both reveal a societal hunger to extend the human life span.

Moreover, they have in common that the individuals presented seem to try to defy the cultural imaginary established for them. This cultural imaginary is, ironically, also prevalent within all these narratives. Here, the internationality of cultural imaginaries of aging becomes apparent. Although I have discussed narratives from the U.S., Canada, the U.K., and Belgium, the fabrication of the archetypes of centenarians as well as of children with progeria remain very similar. When looking

at the fabrication of these concepts and the defiance of it, it is important to note that the narrative structure in both sets of narratives is very similar. They are all collaborative works which—more or less—present the perspectives of the centenarians or children with progeria as well as those of their collaborators. While it can be criticized that agency is often taken away from the individuals presented in these narratives, the attempt to untangle different voices within the stories has proven to be fruitful as it allows for a reading of different perspectives. These shifts in perspective between children with progeria or centenarians and their co-authors, directors, or even parents show how both centenarians and children with progeria are fabricated by others. This fabrication includes a notion of otherness, allowing for a commodification in both cases. Looking at the perspectives of the extraordinary aged themselves allows for a more nuanced discussion of the aging experience itself that is not defined strictly by the binaries of age stereotypes. Both types of narrative thus reinforce *and* go beyond stereotypes of ‘old’ age and help to understand how these stereotypes are arbitrary and oversimplified. They show the complexity of the aging process and the complexity of lived experience as a whole.

Beyond the depiction of the aging process, narratives of extraordinary age show how age(ing) is influenced by outside factors. The imaginary of the body is not only defined by a specific moment in history, as Jurecic argues, but also by very specific cultural and social contexts. In that connection, age(ing) throughout the course of life is defined by other differences: Gender, class, and race in all cases discussed appear to be defining categories of a person’s life, influencing the way age(ing) is portrayed and experienced, even in narratives that specifically deal with age and the aging body.

But what does this mean for an aging process that would be considered normal by broader society? At the very least, it shows that stereotypes of age(ing) and the expectations that go along with them are tremendously strong. Individuality, it seems, ends with being considered an ‘other’ in terms of one’s body. In these cases, cultural imaginaries are established that supposedly define a person’s existence. Reading the narratives of extraordinary age against the grain, however, shows a sense of defiance against these stereotypes by pointing to the fact that there is no norm in the first place and that every person is ‘different.’ The narratives at hand are thus both: the modernist façade of a category and the postmodernist attempt to break it down. Moreover, the need for these overtly positive narratives shows the inherent fear of growing ‘old.’ Only because we are afraid of the later years in life, or scared of falling ill, we thirst for narratives that paint a general picture of the positive. However, I argue, tying into this public demand does not help solve the problem. The general fear, that easily turns into discrimination, can only be fought by providing diverse narratives. Especially those that embrace imperfection and drive home the point that it is okay to experience setbacks in life. We need those narratives that show how there is perfection within imperfection and encourage

all people to indulge in their individuality, not stigmatize them for it. Depending on the perspective, narratives of extraordinary age(ing) can thus be both: an oversimplification or a counter narrative.

This study has set out to renegotiate age(ing) at the intersection of biology, society, and culture through the analysis of narratives of extraordinary aging processes. While the discussion has provided many insights into alternative imaginaries of age(ing), it has also shown the limitations of language. The already existing cultural imaginaries have shaped a way to think and speak about the aging process. Although I have attempted to break with this language by establishing a set of sub-categories of age(ing), the cultural and social structures I move within limit the framework. Because of mechanisms of socialization and language, it is next to impossible to think about age(ing) outside of chronology. Thus, although attempting to provide a new angle, my analysis has often fallen back into the cultural discourses it criticizes. A lack of language to discuss age(ing) without the constructed frameworks of life-stages and chronology then raises the question whether we can even understand phenomena that are so ingrained into our systems in another way than how they are constructed. Nevertheless, I have shown how narratives of extraordinary age serve as an entry point into the realms of the culturally undetermined which could be expanded in future research, for example, by connecting these finding to speculative narratives on age(ing) which can stretch normative assumptions about the process and the concept to an extreme.

