

JULIA VELTEN

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# EXTRAORDINARY FORMS OF AGING

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LIFE NARRATIVES OF CENTENARIANS  
AND CHILDREN WITH PROGERIA



[transcript] Aging Studies Volume XXIII

Julia Velten  
Extraordinary Forms of Aging

The series is edited by Heike Hartung, Ulla Kriebnernegg and Roberta Maierhofer.

**Julia Velten**, born in 1989, works as an assistant professor at the Obama Institute for Transnational American Studies at Johannes-Gutenberg-Universität in Mainz. She received her doctorate from there in 2021. She was a member of the DFG Research Group “Un/doing Differences: Practices of Human Differentiation” from 2016-2019 and was hosted as visiting PhD student at the Trent Centre for Aging and Society in 2017. Her research focuses on aging, medical humanities, and indigenous studies.

Julia Velten

## **Extraordinary Forms of Aging**

Life Narratives of Centenarians and Children with Progeria

**[transcript]**

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# Introduction

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Age(ing)<sup>1</sup> is a concept familiar to everyone. We all hope to age through the life-course and to ultimately grow ‘old.’<sup>2</sup> Moreover, we see age(ing) everywhere: in our friends, neighbors, parents, and in ourselves. Because of this omnipresence of age(ing) in our everyday lives, the concept itself, the way it is constructed and perceived, and the way it affects individuals as they are aging through the life-course often appear to be trivial. This is not, as I argue throughout this study, because age(ing) is insignificant to an individual’s life, but because it has been normalized through its omnipresence.<sup>3</sup> Aging, allegedly, is just something that happens and therefore nothing to consider more closely. In order to disrupt the supposed normalcy of age(ing), this book discusses extraordinary forms of ageing, that is, examples of people whose aging processes are outside an expected aging norm and therefore make the mechanisms behind age(ing) visible.

Fictional stories, such as F. Scott Fitzgerald’s “The Curious Case of Benjamin Button” can provide narratives that upset the imagined normative life-course by presenting alternative models of age(ing). Fitzgerald’s short story deals with the life of a person who is born as an ‘old’ man, ages backward throughout his life-course, and finally dies as a baby. Besides criticizing the need to conform to an expected norm when it comes to the aging process—although an ‘old’ man, Benjamin Button is dressed in children’s clothing and expected to act in a way that would be expected from a child—the story presents a discourse of age(ing) at the intersection of the cultural, social, and biological.<sup>4</sup> In terms of aging as a cultural process,

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- 1 I use this form of notation when I am speaking about the aging process as a whole, as well as age as a construct. Age(ing) is hence a convenient short form of the expression ‘age and aging.’
  - 2 I consider concepts of ‘old’ and ‘young’ to be arbitrary imaginaries and therefore use the terms in quotation marks.
  - 3 The concept of age being a naturalized and therefore largely invisible concept goes back to Charyl Laz. The claim that age needs to be made visible through certain “wake-up” calls is connected to Mita Bannerjee and Norbert Paul. Both arguments and their connection to one-another, as well as to the topics of this book will be further elaborated on in chapter 1.
  - 4 Throughout this book, I keep referring to the intersection of the cultural, social, and biological. I define the cultural aspect of age(ing) as the imaginaries established through language,

Fitzgerald's story shows that there are imaginaries of the life-course that are culturally constructed. Mr. Button announces that his son Benjamin should wear a blanket because "[b]abies always have blankets" (163). Apparently, he is not concerned about the actual needs of his child but about the cultural construct of what a baby should be like. Hence, these constructions lead to expectations according to the imaginaries of the life-course established in a certain culture. The narrative of Benjamin Button suggests that if these expectations are not met, the individual becomes a social outcast, thus showing that the cultural and the social are inextricably linked. Mr. Button is concerned about his reputation and about his social role when he realizes that his newborn son looks like a septuagenarian, worrying about "[w]hat will people say" (163). In the case of Benjamin Button, the social roles attached to a life stage and the cultural imaginaries that go along with them are juxtaposed with the biology of a body aging in reverse. Thereby the story indicates that while there is a biological reality to any aging process, this reality may stand in stark contrast to cultural and social aging norms.<sup>5</sup> Ultimately, "The Curious Case of Benjamin Button" suggests that the physical aging process, concerning both body and mind, may be an important factor in the overall construct of age but that it is largely influenced by cultural images and social expectations, as well.

Connected to these cultural and social expectations, Margaret Morganroth Gullette claims in her monograph of the same title, that we are "aged by culture," meaning that more than an aging body, the cultural imaginaries that are connected to it, define the way we age. Hereby, Gullette compares the aging process to other imagined categories of difference as she argues that "[i]n age, as in gendered and racialized constructs, relations of difference depend on the dim of representations, unseen internalizations, unthinking practice, economic structures of dominance and subordination" (*Aged by Culture* 27). While age is, according to Gullette, a cultural construct, its construction does not happen consciously but is the result of internalized processes that remain mostly invisible in everyday life. This cultural imaginary, I argue, is integral in defining an individual's role within society. Fitzgerald's fictional account of the aging process works to question age(ing) and the life-course alongside the normative expectations attached to them. Consequently, the story

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media representations, and the narratives discussed. The biological encompasses the physical and medical aspects of age(ing), that is, all those aspects related to the aging body. The social strictly refers to an individual's role within society. While this position is highly influenced by the cultural and the biological, I understand social roles as another factor in the construction of age. Consequently, I argue that the social role of an individual influences the way the aging process is culturally perceived as well as the effects the aging body has on the perception of a person's age. Although I refer to these concepts separately, I am aware that they are often inextricably linked and not clearly distinguishable from one-another.

5 For detailed elaborations on the connections of narratives and the body, cf. Banerjee *Biologische Geisteswissenschaften*.

questions the defining power this normative imaginary of age(ing) has over life itself. By breaking free from the expected life-course, the narrative presents an alternative storyline of a life lived. Thereby it disrupts the assumption that people at a specific stage in life automatically conduct themselves a certain way and instead suggests that there needs to be a more flexible understanding of the life-course. Moreover, the story illustrates that it is not only the body that has the power to determine the way we perceive age(ing), rather, accompanying social structures and cultural imaginaries are decisive as well. By disrupting the process of aging which, in its normativity, usually remains largely unnoticed, the story presents it as the main focal point for the reader. This disruption of normativity makes the aging process visible, allowing for observation beyond the expected.

While “The Curious Case of Benjamin Button” invites readers to engage critically with normative assumptions of age(ing) in terms of the interplay between biological processes, cultural imaginaries, and social roles, today’s media representations, especially of ‘old’ age, appear to be much less nuanced. Especially prominent is a tension between the assumption that “aging equals decline” (Gullette, *Aged by Culture* 7)—painting a rather negative picture of isolation and physical decay in ‘old’ age while, at the same time, idolizing being ‘young’<sup>6</sup> as good and positive. The positive connotation of being ‘young’ leads to a general desire to remain within this age category as long as possible, inspiring an imaginary of “successful aging,”<sup>7</sup> a concept discussed by John Rowe and Robert Kahn in their study of the same title. The concept of successful aging considers those individuals a success who have maintained a physically fit body throughout their lives and remain active in ‘old’ age (Rowe and Kahn 38). Both representations of ‘old’ age—decline and successful aging—are, at the same time, result and cause for the cultural imaginary of the age(ing) process as a conglomerate of binary structures: ‘young’ and ‘old,’ progress and decline, successful and unsuccessful.

Fictional stories like “The Curious Case of Benjamin Button” offer the unique possibility to turn normative structures of age(ing) on their head, to imagine scenarios that break with these binaries, and to negotiate alternative cultural images of the life-course. At the same time, these imagined stories fall short of capturing lived experience as they portray a speculative aging process, far away from the biological processes of the world. In that connection, Kay Schaffer and Sidonie Smith

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6 With the arbitrariness of the concept of being ‘young’ in mind, I would like to nevertheless specify the terminology. When I refer to a ‘young’ age, I refer to the time in a life that is, in western cultures, associated with beauty, fitness, economic strength, and health. Therefore, the term in itself is very broadly applicable from the time between early adulthood to early midlife, which are again concepts that are impossible to clearly define.

7 What Rowe and Kahn term successful aging is also often referred to as positive or active aging. I will use these terms synonymously.

argue that a component of 'reality' may give more weight to a narrative (1) and that "[t]he desire for personal stories, often telling of individualist triumph over adversity, of the 'little person' achieving fame, of people struggling to survive illness, catastrophe, or violence, seems insatiable in the West" (25). While criticizing the sensationalism inherent to personal stories, as well as the portrayal of individual struggle instead of broader communal issues, the scholars also advocate for the need of life narratives in addition to fictional accounts, for conveying meaningful stories that encourage the audience to change their perspective on the topics presented. Schaffer and Smith explain that narrated lives may "issue an ethical call . . . for institutions, communities, and individuals to respond to the story; to recognize the humanity of the teller and justice of the claim" (3). Live narratives, presented as 'real' human stories, according to Schaffer and Smith, implicitly attempt to have their audience react to the story and rethink ethical issues or issues of justice that occur within these narratives. A sense of 'reality' within life narrative thus leads to a pondering of the presented stories in a way that directly connects the story to the experience of the reader.

Contrastingly, fictional stories such as "The Curious Case of Benjamin Button" manage to disrupt normative assumptions about the aging process by presenting extraordinary events that cannot be 'true.' This disruption moves the core message away from the reader's own experience who is aware that aging backward is highly unlikely, if not impossible. Life writing, on the other hand, is presented with the opposite problem: Life narratives are directly tied to lived experience and are therefore limited in their scope. In other words, there is no life narrative of aging backward because the phenomenon does not exist. In that connection, life narratives are bound to a code of ethics which, according to Paul Eakin includes that "[w]hen life writers fail to tell the truth, then, they do more than violate a literary convention governing nonfiction as a genre; they disobey a moral imperative" (2-3). Having to obey to the moral imperative of telling the 'truth'—or whatever a person regards as their truth at a certain point in time—restricts life narratives from being speculative. This may lead to an inability to disrupt normative expectations of age(ing) in life writing, as age(ing) is often believed to happen automatically on the sidelines and is therefore considered normal. In that connection, Gullette calls for "critical age autobiography" ("From Life Storytelling" 103), aiming to focus on an individual's process of being 'aged by culture,' a process which establishes what she calls "life-course imaginaries" (102). Gullette advocates for a more distinct reading of age(ing) within life narratives. While I aim to provide these age conscious readings throughout this study, I furthermore aim at discussing narratives that upset the age(ing) norm, making, as I will argue throughout this book, age(ing) as a process and a construct more visible to the audience. My aim is thus to bring together the power of fiction in the sense that fictional texts can tell extraordinary stories and disrupt expected norms through speculation and the power of life narratives

assuming that their negotiation of lived experience and sense of ‘reality’ present indications on age(ing), ethics, and the human life-course, speaking directly to the audience’s own ‘realities.’ I therefore look at extraordinary cases of age(ing)—cases that appear almost fictional to the audience—in life narratives, arguing that the unexpected life-courses presented have the power to disrupt ‘life-course imaginaries’ while at the same time negotiating the lived experience that goes along with this disruption.

This study sets out to investigate narratives that, on the one hand, disrupt the normative and make age(ing) visible and, on the other hand, fall into the category of life narrative and thus cater to Western society’s desire for stories of lived experience. I generally regard this ‘insatiable desire’ as highly critical, for it encourages the thirst for sensationalist stories, ultimately turning their subjects into objects of mere entertainment for the masses. Yet, an analysis of these stories offers the singular possibility of shedding light on the way society looks at certain, typically excluded topics, in this case extraordinary forms of aging. I am therefore interested in two extraordinary forms of age(ing): those individuals who live exceptionally long and those whose aging process is accelerated. In the course of this study, I will look at life narratives of centenarians and children with progeria, exploring how these stories of extraordinary age(ing), may disrupt normative assumptions, make visible cultural structures that influence age(ing) and, ultimately, how they may provide a more nuanced imaginary of life, care, and age(ing) at the intersection of the cultural, social, and biological. Besides providing narratives that counter normative expectations, both forms of age(ing) present to be extremely sellable. In that connection, this study goes beyond looking at the cultural imaginary of age(ing) within these narratives and also investigates how this imaginary is formed through the means of production, narrative structures, and the people involved in telling the stories.

Centenarians, considered “paragons of positive aging” (Robine and Vaupel x), seem to present a counter narrative to imaginaries of decay and decline. By framing exceptionally ‘old’ age as an achievement, narratives about and by centenarians focus on ability rather than decline, establishing centenarians as beacons of health and physical fitness. Centenarians go beyond what is culturally expected in terms of their aging process simply because they live extraordinarily long. At the same time, narratives dealing with centenarians always appear close to the pitfall of reinforcing a successful aging paradigm, as they promote an aging process that goes beyond what Rowe and Kahn call “usual aging” which is defined as being “on the borderline of disease” (53). The term and accompanying paradigm of successful aging is thus entrenched with notions of neoliberal societies that make their members responsible for their own health status. If centenarian narratives tie into this paradigm, they are also part of the establishment of a new cultural normal where healthy and independent ‘old’ age is imagined to be the imperative. And yet, living



to 100 is not considered normal at all, as, despite ever growing numbers of centenarians, most people do not reach this imaginary threshold. It is this intersection of a new normal and the extraordinary that makes looking at centenarian narratives so fruitful: How are age(ing), loss, (dis)ability, in(ter)dependence, care, and individuality portrayed at this intersection? How does deviating from a supposed norm influence the way age(ing) is negotiated socially, culturally, and biologically?

Children with progeria, at first glance, seem to present a completely different basis of negotiation. Yet, despite the initially expected fundamental divergence between the two, centenarians and children with progeria are connected by the extraordinary nature of their aging processes. Progeria is a medical condition that lets parts of the human body age about seven times faster than that of a normative ager. Ray Kreinekamp and Susana Gonzalo elaborate that progeria “does not totally recapitulate normal aging [but] it does harbor many similarities to the normal aging process, with patients also developing cardiovascular disease, alopecia, bone and joint abnormalities, and adipose changes” (1). This biological process leads to an ever-present connection between progeria and the aged body. In narratives dealing with progeria, the biological condition of the body challenges the cultural construction of age and, at the same time, questions binaries of ‘old’ and ‘young.’ While these children are considered to age according to normative expectations in terms of their minds, their bodies make their aging processes deviate from this norm. Closer inspection reveals that, although they arrive there from different roads, centenarians and children with progeria are situated at the same intersections between the biological, social, and cultural, as well as the normative and the non-normative.

As Schaffer and Smith suggest, the interest in life narratives is prominent in Western cultures in general. I assume throughout this book that there is not only a common interest in this genre amongst these cultures but that there is also a common understanding about general imaginaries of the aging process. Platforms such as *YouTube*, *Facebook*, and *Twitter* make it easily possible to share stories and knowledge across national borders. Popular culture is largely influenced by Hollywood and other U.S. American entertainment formats, transgressing national boundaries, broadcasting all kinds of images, including those of age(ing), into the world. Additionally, North America and Europe share certain neoliberal and meritocratic tendencies, measuring the worth of a person according to their contribution to society and therefore framing an ever-growing population of ‘old’ people as a problem for social and economic structures (Macnicol 2). These commonalities are not only apparent in media representations of age(ing) but also in the scholarship thereof, as for example fundamental U.S. American theories of cultural aging established by Gullette are applied to the aging experiences of other Western cultures. Consequently, the two major research organizations in Europe—the European Network in Aging Studies (ENAS)—and North America—the North American

Network in Aging Studies (NANAS)—have traditionally organized joint conferences and research collaborations. In their mission statement ENAS promises to “facilitate[] sustainable international and multi-disciplinary collaboration among all researchers interested in the study of cultural aging” (“Mission”), thereby connecting scholars across national borders. This study echoes this aim to provide an international approach and engages with narratives from the United States, Canada, Belgium, and the United Kingdom, bearing in mind national and cultural differences but focusing on a shared development of a discourse surrounding extraordinary forms of age(ing).

This book is divided into three parts. The first part outlines the theoretical framework of the discussion of extraordinary forms of age(ing) and provides an overview of the fields of aging studies and life writing research. Furthermore, it highlights the connections between narratives of centenarians and children with progeria in order to set the analytical framework for their discussion.

The second part is dedicated to narratives of centenarians. It consists of three chapters and analyzes different forms of life narratives in terms of their representation of the age(ing) process and their portrayal of extraordinary ‘old’ age. The focus here is placed on the way cultural imaginaries of age(ing) are disrupted or reinforced within these narratives through the portrayal of exceptionally long and exceptionally healthy lives.

The third part then focuses on children with progeria. Also consisting of three narratives, this part explores how the imaginary of age(ing) is disrupted through the premature aging disease and by the juxtaposition of the biological with social expectations and cultural imaginaries.



# **I. Aging Studies amid the Cultural, Social, and Biological**



Age(ing) has many layers and dimensions that are inextricably linked with one another and ultimately form an imaginary of the process of living through various life stages. Although “age studies have long shifted from speaking of ‘periods in life’ (such as childhood, adulthood, old age)” (Banerjee, *Medical Humanities* 134), in public imaginary, these stages are still very much part of the age(ing) discourse, defining how individuals are supposed to ‘be’ at a certain point in their lives. Every individual has personal experiences of their own aging process, as well as encounters with that of their parents, neighbors, or friends. Moreover, there are media representations that influence the perception or expectation of what aging is like for an individual. Despite the complexity of the process and the cultural, social, and biological construct that is age, there are oftentimes many simplifications of the concept. The assertion that ‘age is just a number,’ for instance, is commonly used to, on the one hand, simplify the concept and, on the other hand, diminish the effect age has on the life-course in general. If age is not just a number, however, what is it that makes a person ‘old’ or ‘young’? And what is ‘old’ age? These questions have been discussed frequently by scholars of the interdisciplinary field of aging studies which focuses on cultural aspects of the process. On the other hand, the field of gerontology focuses on biological implications. The field of social gerontology, as a third approach, looks at the way the biological aging process influences social structures. By looking at (social) gerontology and theories of aging studies, I will in the following outline where research on age(ing) has pointed to or neglected the interconnectedness of the social, biological, and cultural. I will trace the overarching concepts in aging studies which I aim to discuss and renegotiate in light of extraordinary forms of age(ing). Further, I will have a closer look at age as a construct, consisting of subcategories itself. I will thus establish the categories I will apply throughout this study. Finally, I will discuss progeria and centenarianism in light of their promise to generate new insights on the way we understand age(ing), as well as the potential the specific genre of life writing brings to the analysis.



# 1 Theories of Age(ing)

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## 1.1 The Beginnings of Social Gerontology: The Biological and the Social

Debates about the aging process go back into ancient societies. Philosophers such as Aristotle, Cicero, and Seneca pondered questions about the life-course and the ways that human nature develops into advanced age. Age(ing) is often regarded in relation with 'old' age, as the stage in life that is most commonly associated with derogatory stereotypes of decay. Andrew W. Achenbaum explains that Roman philosopher Seneca wrote “[s]enectus morbidus est” which translates into “[o]ld age is a disease” (“A History of Ageism” 11). Seneca’s statement focuses merely on the aging body and its tendency to become weaker in later life. In other words, Seneca regards ‘old’ age solely in terms of the declining body, implying that not only is the aging body more prone to fall ill but that ‘old’ age itself is the disease; a terminal one. Considering ‘old’ age to be a terminal disease defines later life as something that befalls the body, weakens it, and, if not cured, kills it. Further, diseases are often contagious, which might lead to the fear that ‘old’ people could infect others with their ‘oldness.’ That fear, in turn, encourages a marginalization and stigmatization of the ‘old.’ Having caught a disease, there are only two possible ways to go: Either one declines and ultimately dies or one receives treatment and fights off the illness that invaded the body. As there is no cure for ‘old’ age, once a person is ‘infected’ with it, there is no going back which leads to an association of ‘old’ age with death.

Even though Seneca’s statement is about 2000 years old, the assumption that ‘old’ age is a disease is still prevalent in modern thinking. This tendency can be seen in the research of scientists such as British molecular biologist Aubrey de Grey who, in an interview with *The Guardian* describes age as “this ghastly thing that is going to happen to [a person] at some time in the distant future” (Smith). De Grey and his SENS Research Foundation have made it their mission to find a ‘cure’ for ‘old’ age. According to their homepage, the foundation envisions “to develop, promote, and ensure widespread access to therapies that cure and prevent the diseases and disabilities of aging by comprehensively repairing the damage that builds up in our bodies over time” (“Home”). In other words, the SENS foundation tries to stop the aging process within the human body, at the same time connecting ‘old’ age



to illness and disability. While other researchers clarify that 'old' age is not a disease, they do however frame it as a 'risk-factor.' Christopher Burtner and Brian Kennedy, for instance elaborate that "[a]dvanced age in humans is considered the largest risk factor for a range of diseases, including neurodegenerative, cardiovascular, metabolic and neoplastic syndromes, raising the possibility that targeted approaches to aging will delay the onset of many causes of morbidity in the elderly" (567). Yet, they also advocate for research that helps slowing down the aging process in general in order to avoid the risks that come with 'old' age as long as possible. Ultimately, these scientific discourses present the aging process as a biological problem that needs to be solved and thus implicitly promote the perception of 'old' age as a curable condition.

As long as aging is not 'curable,' however, its association with disease leads, according to Heike Hartung and Rüdiger Kunow, to the belief that "[t]he later stages of the life course are . . . conceived as something like 'a waiting room' in which people bide their time until they die; a waiting room, moreover, that is mostly populated by women" (18). In connection to 'old' age as disease, the metaphor of the 'waiting room' accumulates several stereotypes of 'old' age: sitting in a waiting room is passive, hence, 'old' people are not expected to be actively involved in life anymore. Secondly, a waiting room is an isolated space, reserved for those in transition to somewhere. Being in a waiting room accordingly means being neither here, nor there, belonging nowhere. Thirdly, waiting rooms are mostly negatively connoted. Not only because of the annoyance of having to sit and wait for something; or the awkward feeling of sitting there with strangers that, for some arbitrary reason, are in the same space at the same time, but mostly because waiting rooms are associated with doctor's offices, a space that is in and of itself linked to illness, suffering, and uncertainty. The link between a physician and a waiting room then also indicates that all people sitting in that room are sick.<sup>1</sup>

Similar images of 'old' age and disease can be traced throughout history. The popular image of the "Lebenstreppe" (Stairs of Life), was prominent throughout Europe from medieval to early modern times. In these images, which can be traced back to Aristotle who divided the human life-course into growth, stasis, and decline, human existence is depicted in the form of stairs, making life an ascent from its beginning up to its middle and a decline from there into 'old' age and death

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1 Hartung and Kunow also hint at the fact that the 'waiting room' of the 'old' is mostly populated by women. That is that statistically women live longer than men and consequently the troubles of ageism are a huge problem especially for the female population. There is extensive scholarship on female aging, precisely because women are statistically more likely to live to an age that is prone to be met by ageism. I will not elaborate on the issue here because it is not one of the main foci of my work. However, I will hint at the differences that are made between female and male aging at various points.

(Cole 5-6). By emphasizing the climb and descent, these images enforce a binary structure of aging that is related to the body. Looking at the stairs of life, it seems that physical strength grows during the first half of a person's life and declines in the second. Connected to this focus on the aging body within the metaphor of an ascending and descending staircase, according to Gullette, today aging is still divided into progress and decline. Fittingly, narratives of progress are usually associated with children (*Aged by Culture* 15) and "the structures that support progress and progress narratives are slowly being withdrawn early or late in middle life from all but the most privileged" (19). In reference to this binary structure, we imagine early life as a constant progress, a climb towards a certain point, or age. Being defined in terms of progress, then, is a privilege of the 'young' who, according to that imagery, still have a strong and healthy body. When the progress narratives are withdrawn, decline sets in and therefore, after the early midlife "[a]ging equals decline" (7). Connected to this imaginary of decline, Gullette describes that in later life "[p]eople see ahead of them, in grim shadowy forms, the prospective life-course narrative that the dominant culture provides—an unlivable mind and unrecognizable body . . . death" (*Agewise* 24). Decline then describes the expected slow decay of the human body and mind that comes with 'old' age and will ultimately lead to death. With the binary oppositions of 'old' versus 'young' implemented in society, we are inclined to believe that while 'young' people have everything, 'old' people have nothing. While 'young' people are beautiful, 'old' people are ugly, while 'young' people are (financially) successful, 'old' people are poor, and while 'young' people are fun, 'old' people are boring. These binaries support the focus on the biology of aging, by reinforcing the assumption that 'old' age really is a disease or at least that 'old' age promotes disease. At the same time, looking at these binaries shows how the focus on the aging body alone inevitably establishes derogatory imaginaries of 'old' age.

Gullette's observations about aging and decline from 2004 follow up on the theoretical movement of the 1950s and '60s that contributed research on the influences of the aging body on the social role of an individual. Consequently, since the term "social gerontology" was coined in the early 1960s by Clark Tibbits, the field has brought forth several concepts describing how age(ing) can influence an individual's social role. One of the early and most known social theories about aging, disengagement theory, was established by Elaine Cumming and William Earl Henry as early as 1961. In their book *Growing Old* they argue that

aging is an inevitable, mutual withdrawal or disengagement, resulting in decreased interaction between the aging person and others in the social system he belongs to. The process may be initiated by the individual or by others in the situation. The aging person may withdraw more markedly from some classes of people while remaining relatively close to others. His withdrawal may be ac-

accompanied from the outset by an increased preoccupation with himself; certain institutions in society may make this withdrawal easy for him. (14)

According to this theory, there is no need in trying to include the elderly into the fast, everyday life of the 'young' because disengagement is inevitable. Be it because of the elderlies' primary focus on themselves, or because of the influence of institutional forces, Cummings and Henry make the withdrawal from certain parts of society sound like a natural step for every person who has reached a certain age. The terminology consists of euphemisms, an 'increased occupation with himself' for example can be read as the claim that elderly people are generally too self-absorbed and ego-centric to interact with other people. Conversely, this reading gives the impression that there is no need to try interacting with the elderly because self-absorbed people do not deserve that privilege. A second phrase that appears to be rather euphemistic engages with institutions making the withdrawal 'easy.' The notion rather is that institutions, ranging from workplace to retirement homes, make it hard for people to stay in touch with society and thereby forcing them into disengagement (Gullette, *Agewise* 1). If the elderly do not disengage voluntarily, but are forced to do so, the make-up of disengagement theory crumbles. Ultimately, Cummings and Henry's disengagement theory reinforces the idea of the isolated 'waiting room.' If the elderly disengage themselves or are disengaged from the rest of society, it puts them into that isolated, awkward space in which they decline toward death.

Furthermore, disengagement theory is frequently connected to the aging body and the influences it has on the way 'old' people act within society. This approach to 'old' age, for instance, has been rediscussed by Heike Hartung and Rüdiger Kunow. They describe disengagement theories as those "according to which the aging body makes necessary a gradual removal from participation in social activities" (17-8). It is, accordingly, not only the increasing need to deal with oneself in 'old' age, but primarily the changing body that disengages the elderly from the rest of society. Assuming that the aging process slows the body down, disengagement theories imply that it would be easier for the aged not to have to keep up with the rest of the world. The theory, of course, can be read as a means of support for the elderly, since it does allow older people to age biologically, without having to be in constant competition with the rest of society. According to this reading, the disengagement of the elderly might actually work against every-day discrimination as well as a social pressure to keep up.

But what would be the consequences of such disengagement? Believing that it is beneficiary to separate 'old' people from the rest of society, makes it acceptable to not interact with them. This may have a twofold effect: First, it could increase the number of people who use the social separation from their parents or grandparents in nursing homes to truly disengage from them. Second, by actively working

towards a separation of the elderly from the rest of society, we actively destroy representations of 'old' age within everyday life. Without representations, it becomes much easier for ageist stereotypes to take the floor. Further, the lack of representation and likewise the negative stereotyping of 'old' age heighten the fear of 'young' people to grow 'old' and deny the prospect of being happy in 'old' age. This is especially noteworthy since, as Kathleen Woodward points out, age "is the difference we must all live *with* because it is the one difference we are all likely to live *into*" ("Introduction" x). By not living *with* the difference of age because we believe in disengagement, we thus construct our own future status as belonging to an isolated, discriminated social group. Woodward's elaboration hints at the problem of the biological versus the social component of aging: Neither the biology of the aging process itself nor the biological effect aging has on the body are deniable. It is therefore important to navigate where the biological aspect ends and the social one begins. In disengagement theory, the biological determines the social, dictating that 'old' people are restricted in terms of physical functions and are therefore unable to take part in the social life of the 'young.' A focus on the disengagement of the elderly is thus a medicalization of 'old' age which leads back to the popular image of 'old' age as decline.

Furthermore, according to Achenbaum, it is because of the disengagement of the aged and the focus on the aging body that "elderly people are often stigmatized by prejudicial words and deeds expressed by other members of their healthcare team. Nurses tend to rate their aged patients as more dysfunctional than indicated by objective measures" (*Older Americans* 83). Highlighting the biology of age leads to questionable judgement even among professionals. This professional judgement, in turn, reinforces the image of the elderly as fragile and in need of their own isolated space. In other words, disengagement leads back to Seneca's 2000-year-old claim that 'old' age is disease. Ultimately, disengagement theory evokes stigmatization of the elderly, which gerontologist and psychologist Robert Butler termed 'ageism' in 1969. Because of the many shortcomings of disengagement theory discussed here it has been frequently criticized by scholars of aging studies. Hence, Hartung and Kunow state that "[o]ld people are perceived (and often wrongfully so) as either having or being withdrawn from the overall interactional processes of society and culture" (16). While in the academic world the assumption of withdrawal of the 'old' from society is thus criticized, the notion of disengagement is still a large part of the cultural imaginary of 'old' age.

The medicalized image of 'old' age, however, has recently led to a counter narrative of age(ing), promoting physical fitness in order to promise an active and healthy life into 'old' age. This successful aging paradigm is described by John Rowe and Robert Kahn in order to counter the "myths of aging" connected to decline (11). They "define successful aging as the ability to maintain three key behaviors or characteristics: -low risk of disease and disease-related disability; -high mental and

physical function; and -active engagement with life” (38). This approach to age(ing) counters notions of disengagement due to physical decline by stressing physical fitness instead. Thereby it perpetuates neoliberal discourses of failure versus success, opening up yet another binary of ‘old’ age.

Theories of decline, disengagement, and successful aging are closely tied to the influence of the aged body on an individual’s life and their status within society. Thereby they disregard the weight social structures themselves, as well as cultural imaginaries may have on later life. In the next section, I will therefore elaborate on approaches to age(ing) that try to move beyond the biology of it, toward the defining power of the social and cultural realms of the process. Early works of social gerontology thus focus on the way the biology of aging influences the social role of a person. Hence, biological age has the power to determine if a person is part of the everyday practices of a given society or not. In the next section, I will proceed to discuss the ways these social roles are enforced through cultural imaginaries about the aging process and how in turn social structures influence the way we age.

## 1.2 Social and Cultural Impacts on the Aging Process

It was Margaret Morganroth Gullette who called for the formation of a field called “Aging Studies” in order to undo “the erasure of the cultural in the sphere of age and aging” (*Aged by Culture* 102). She demands a focus on the aging process as culturally determined. By arguing that we are “aged by culture,” Gullette explains how meaning is assigned to age(ing) through the way it is presented in an everyday context. In that sense, age is made an important means of differentiation by society because we attach cultural meaning to it. In this connection, Gullette claims that “[m]aybe age studies should argue that subjects have *no* age until that first markable age-linked sentence falls” (109). In other words, we remain oblivious of age(ing) and what it means until someone makes an explicit statement about it and *teaches* us that there are rules, privileges, and meanings attached to it. Hence, it is only through cultural discourse that we are even aware of age(ing).

Hanne Laculle and Jan Baars take the argument one step further and refer to “cultural master narratives” of aging which play an “essential role in shaping our identities and creating meaning, they can also impend meaning-generating processes, by oppressing or marginalizing certain social groups” (36). Cultural master narratives, or what we experience as cultural representation of a certain age or life stage, influence the way we perceive our own age and that of others. At the same time, they impact our behavior according to social expectations concerning our age. As mentioned above, a cultural master narrative of disengagement then leads to the impression that, as soon as a person reaches a certain age, they are obliged to isolate from social life.

The cultural imaginary of what 'old' age is like, is linked to the human body, connecting back to theories of biology and aging mentioned above. Because Western cultures assume that 'old' age equals decline and social isolation, they create derogatory images of it. Accordingly, Gullette explains that "[o]nce [decline] has tinged our expectations of the future . . . with peril, it tends to stain our experiences, our views of others, our explanatory systems, and then our retrospective judgement" (*Aged by Culture* 11). If decline is the dominant discourse of the later years of life, like disengagement, it triggers negative expectations for 'old' age and influences the role 'elderly' citizens take up in society.

In addition to expectations of physical decline, similar images are prevalent when it comes to age related dementia and Alzheimer's disease. Marlene Goldman argues that "[t]he media frequently adopts a Gothic and apocalyptic perspective on Alzheimer's disease" (4). Culture in form of media representations thus provides the expectation of dementia as a horror story, connecting age(ing) to fear. This notion of decline in a physical and mental way as a cultural imaginary shows how the process of being "aged by culture" is infused by concepts of the aging body which, for the purposes of this study, includes the brain and hence the mind.<sup>2</sup> In fact, it is impossible to clearly disentangle the cultural aging process from its biological influences. Theories that are influenced hugely by the biology of the aging body turn into self-fulfilling prophecies: because we believe in the cultural discourses of decline and disengagement that accompany the aging process, we are likely to experience them ourselves as soon as we enter the realm of the aged.

In order to distance themselves from the biologically and medically dominated theories of age(ing), scholars of aging studies have drawn from other theories in order to create new discourses surrounding the aging process. The most prominent collaboration emerged between aging studies and gender studies. The connection is especially fruitful because gender studies also encounter the dualism of biology and social gender roles. In gender studies, this problem has been addressed by the terminology of sex versus gender in order to be able to distinguish between the biological (sex) and the social (gender). In that connection, Charyl Laz argues that "just as sociologists have distinguished the 'objective' and the 'social' components of sex and gender and at the same time analyzed their reciprocal relationships, so we have begun this same line of analysis in age study" (*Act your Age* 93). In other words, aging studies can learn the mechanisms of distinguishing between the social and the biological, as well as how to look at their interaction and their being influenced by cultural imaginaries from gender studies.

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2 Debates about the dualism of body and mind are diverse and complex. My aim here is not to engage in these debates. I rather regard mental decline as a part of the expected physical decline of the body. This approach suggests itself because dementia is an integral part of decline narratives. Nonetheless, mental fitness will not be the focal point of my analysis.

In reference to Judith Butler's theory of the performativity of gender (906), it could be argued that age itself is also an act. Laz elaborates on that by writing that "[a]ge is an act, a performance in the sense of something requiring activity and labor, and age is normative. Whether we do it well or poorly, according to the dominant rules or not, our accomplishment of age—indeed age itself—is always collective and social" ("Act Your Age" 86). In that sense, age can also be described as a fixed set of rules we have to act upon in order to be accepted in society. We are caught within the normative rules that are given to us at a specific point in our life just as a woman is caught within the normative rules that are given to her because of her being a woman. Consequently, just as the domestic sphere was, and still somewhat is, assigned to women, spaces of disengagement that is, spaces away from the 'young,' are assigned to the elderly population. Ultimately, elderly people do not necessarily face disengagement, loneliness, and decline because of their aging body, but because they take up a social role that was constructed based on cultural expectations. As opposed to gender, age however presents different performances throughout the life-course. Moreover, while gender has been accepted as a fluid concept that can be disconnected from the biological sex completely, in age(ing) the biological, cultural, and social remain inextricably entangled.

A rather recent discussion about approaches to 'old' age has emerged through a 2016 issue of the *Journal for Aging Studies*, discussing the implications a postcolonial lens might have on the discourse of aging. Kunow, for instance, sees a connection between postcolonial theory and aging in the "binary opposition (much attended to in postcolonial criticism) between an inside—smelly, unpleasant, and old—and an outside, fresh, and promising, and young, between the open and closed spaces, movement vs. confinement, etc." ("Postcolonial Theory" 103). Kunow thus sees a common ground in the binary relationship of 'old' and 'young' to the binary relationship between the colonizer and the colonized. Keeping this similarity in mind, aging studies scholars could for example draw from Gayatri Spivak's work and inquire about the voice the elderly population, as the subaltern, has in Western society. Van Dyk, for instance, argues that "[w]ith the aid of postcolonial analyses, we are able to see that the stable yet flexible 'superiority' of midlife as a universal benchmark accounts for an ongoing devaluation of the Third Age<sup>3</sup>" (van Dyk "The Othering of Old Age" 115). In that sense, people in their middle age become the cultural superior, the norm that everybody must aim for. An individual that is not part of this superior group automatically becomes the inferior 'other' who is forced

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3 Van Dyk, as well as many other scholars of aging studies, distinguishes between the third and forth age of life. The third age describes those 'old' individuals who are an engaged part of society, able to live independently, being in good health and financially stable. The forth age includes people who are in need of care, sick, and not able to take part in everyday life anymore.

to live by the rules of the dominant culture of the midlife. This superiority of the midlife, in turn also entails superiority over children and the adolescent.

Nevertheless, there are many differences between the study of age and the study of post colonialism. The most prominent one might be that looking at aging, we have to bear in mind that people inevitable develop into the inferior culture of the aged and look back on their own times in the superiority of the midlife. In that connection, Kunow comes to the conclusion that “conceptual needs which post-colonial theory is speaking to are related to but not congruent with those of aging studies” (“Postcolonial Theory” 1066). As with the relations to gender studies, we thus have to be careful to make sure that we acknowledge both, the commonalities and the differences of each theory we are drawing from. Nonetheless, as van Dyk mentions, there are certain mechanisms of othering inherent in the aging process, which I will trace throughout this book. Ultimately, working with postcolonial theories leads to similar conclusions about the cultural makeup of age as we have seen above: Youth is good, whereas ‘old’ age is bad.

In that connection, Kathleen Woodward states that U.S. society falls victim to the “ideology of American youth culture, where youth is valued at virtually all costs over age and where age is largely deemed a matter for comedy or sentimental compassion” (“Performing Age” 164). As an ideology, being or acting ‘young’ is a necessity in order to be accepted in society. ‘Old’ age as a comic element of life has the consequence of elderly people not being taken seriously. At the same time, a comedic portrayal of ‘old’ age calls for sentimental compassion and turns ‘old’ people into victims. They are seen as helpless individuals who need to be pitied for the situation they are in. In both cases, they are not fully acknowledged members of society. This is precisely why Gullette suggests that “in the United States, telling progress narrative in middle life and even old age has become almost obligatory” (*Aged by Culture* 26). Hence, because ‘old’ age is heavy with negative connotations, according to social structures of neoliberalism and meritocracy, it is expected from U.S. citizens to deny their own decline as long as possible, trying to convey an image of progress to the rest of the world. Writing one’s own progress narrative is thus the only possibility to escape from the power of the cultural stereotype of decline.

But how is a person supposed to convey progress in later life? If decline tells the story of the decreasing capabilities of a human being, starting at a certain age, how do we narrate our lives in terms of progress? Gullette answers these questions by explaining that progress narratives are “stories in which implicit meanings of aging run from survival, resilience, recovery, and development, all the way up to collective resistance to decline forces” (*Aged by Culture* 17). Hence, in order to overcome cultural expectations of decline, we need to constantly prove that we are not declining. In public imaginary, this often works by dying our hair as soon as it shows strands of gray or prove physical fitness by participating in marathons. Ultimately, understanding the concepts of progress and decline is crucial to understand the



mechanisms of ageism in society. Against this backdrop Gullette writes that “[a]ge studies might help explode the binary [between progress and decline]. But until it does so, progress narrative—as the only apparent alternative to decline—is almost obligatory” (*Aged by Culture* 19). Gullette thus suggests that there is a need to ultimately disrupt the binary opposition of age. Yet, she sees progress narratives as a means to at least question decline until the binary is resolved.

The focus on progress in ‘old’ age, which intends to counter cultural images of decline and disengagement, led to a discourse of positive or successful aging. By emphasizing that there are ‘old’ people who are capable of living an active life, discourses of successful or positive aging try to undermine discourses of disengagement and decline. As well as the concepts of decline and disengagement, successful or positive aging paradigms have a biological component that then translates into the cultural imaginary of age(ing). Debbie Rudman explains that “[p]ositive aging discourses . . . outline idealized ways to age that involve remaining youthful, healthy, productive, socially engaged and self-reliant, have become central to national and international approaches to governing aging populations, gerontological theory and research, and popular media” (11). Positive aging then emphasized the possibility to age without feeling the cultural connotations of decline and disengagement. Whereas focusing on positive aspects in later life or positive aspects within the aging process appears to be a good way to go, positive aging discourses have been subject to major scholarly criticism. In that connection Rudman elaborates that “Western nations have raised concerns regarding how such discourses have intersected with neoliberal rationality such that responsibilities for the management of bodily, financial and social risks of aging have increasingly been shifted from states and other institutions to individuals” (11). From a neoliberal perspective, it would be an individual’s duty to age positively by adopting a healthy lifestyle. From the state’s perspective, people who age positively are less inclined to fall ill, they are able to remain part of the workforce longer, and they are less likely to need long term care in their later years. At the same time, neoliberal approaches to positive aging suggest that, if people do get sick, need to stop working, or need long term care, they have failed society because they have not managed to age successfully. By trying to overcome narratives of decline, positive aging thus falls into the trap of establishing yet another binary. Instead of ‘old’ versus ‘young,’ discourses of positive aging set the ‘right way’ to age up against the ‘wrong way’ to age. People who remain capable of engaging in ‘young’ activities are regarded in a socially engaged way and are still accepted in a public social sphere. Those who do not engage in these activities are not only subject to stereotypes of ‘old’ age as decline and disengagement, according to neoliberalist standards, they also have to blame themselves for not being as healthy as other people their age. Ultimately, discourses of successful or positive aging do not work against ageism. Rather, they contribute to ageist readings by suggesting that some ‘old’ people are good, whereas others

are bad. This approach to positive age focuses on the process of aging as well as the product of it: Positive aging accordingly asks people to live healthy lives in order to be able to become a 'good' elderly person.

Another approach to successful aging emphasizes the role the 'old' may play within society and how their state of being 'old' could be redefined into something more positive. According to Stephen Katz, the discourse of positive or successful aging asks people to "grow[] older without aging" (*Cultural Aging* 199), meaning that the aging body is supposed to be hidden by anti-aging measurements and that people, while aging, need to act 'young' in order to remain accepted members of society. This, according to Katz, does not only serve the purpose of promoting an active lifestyle in order to establish a cohort of successfully aged people but also serves the economic purpose of triggering a positive aging consumer culture. Katz explains that "this movement has inspired real estate, financial, cosmetic, and leisure enterprises to target a growing and so-called 'ageless' seniors' market (usually pegged at 55+) and to fashion a range of positive 'uni-age' bodily styles and identities that recast later life as an active, youthful, commercial experience" (*Cultural Aging* 190). If elderly people remain part of consumer culture, their economic contribution can continue even after they have left the work force. Accordingly, a person is spared from disengagement as long they are able to consume goods. Ironically, the items marketed specifically for elderly people are often those that promote the process of growing older without aging, or at least those that extend independence in later life. As such, the market remains intact by keeping elderly people consuming products that let them seem younger for as long as possible while, at the same time, recruiting new customers every day by demonizing the signs of 'old' age. Anti-aging cream commercials, for instance, promise to make skin less wrinkly and to hence fight the outward signs of 'old' age. Implicitly, they convince the audience that wrinkles and therefore 'old' age in general are negative. Hence, we are inclined to buy the cream in order to avoid aging while growing older.

Positive aging thus establishes a whole new consumer market for the elderly population, on the one hand making them valuable for economy and on the other hand dictating that they can only take part in the world as long as they stick to a 'young' lifestyle. According to Marvin Formosa, "[p]ositive aging is, therefore, guilty of age denial. It focuses its energy and efforts on celebrating and propagating the so-called 'third-age lifestyle,' and in doing so, promotes its ethos at the expense of older and more defenseless people, namely those in the fourth age" (30). Accordingly, positive and successful aging discourses suggest that those who are 'active' are actually not yet 'old' and can therefore be a vital part of society. Those who cannot be active anymore are moved out of the focus of the theory, connecting them to the ageism surrounding disengagement and decline. Promoting positive aging is then not fighting ageism and the binary structures of the life-course, rather, it makes sure that in addition to being marginalized because of 'old' age, people have

to fear to be blamed for said marginalization themselves. In fact, age denial then means denying the change of a human life throughout the life-course. If we are expected to grow 'old' without aging, 'old' age is denied any positive aspect to it because it has to be avoided at all costs. If we do it right, according to this theory, we will not change from the self that we were in midlife. If a person is unable to 'grow old without aging,' it seems that, according to positive aging discourse, they deserve to be an outcast to a society of the 'young.'

Other approaches to age(ing) and the life-course focus on meaning as a parameter to measure value in 'old' age. Ricca Edmondson, for instance, suggests to redefine lives in terms of meaning and establishes three categories of meaning: First, connectedness with other people; second, development through time; and third, insight into the human condition (102). Being connected to other people and, in turn, not being isolated provides a meaning- and purposeful life. Development gives us the approval that our lives are going somewhere, that we are not stuck in the same patterns and, ultimately, that we are able to achieve something. Gaining insight into the human condition means to accomplish a certain form of wisdom, but also the common sense on how to interact with the world. Reading 'old' age through the lens of meaning, shifts the focus away from active or positive aging and rather asks if a person sees their life as meaningful. Discourses of meaningfulness attempt to break with the binaries of aging and suggest a new set of questions we can address to the life-course at any stage.

The importance of meaning at any life stage is also prevalent within the collaboration between aging studies and disability studies. Age(ing) and disability are connected because both are prone to be regarded from a standpoint of physical impairment only. Sally Chivers describes the connection:

Claiming that old age is *not* disability (i.e., refuting the cultural conflation) risks implying that disability is a negative that age theory could do without. But to claim old age *is* disability would be to appropriate key aspects of disability and thereby risk effacing issues related to aging with disability. To my mind, old age is akin to disability in the ways they are socially constructed—not just *that* social barriers define both but that they are both constructed as bodily, threatening, and signaling failure. In fact, the similarity comes precisely from the continual failed attempt to enforce a clear distinction where one is simply not possible: between a social element (often called 'disability' in disability studies) and biological element (often called 'impairment' in disability studies). (*The Silvering Screen* 23)

This elaboration not only shows that there is an inherent link between age(ing) and disability in the way they are both culturally imagined but that there are also difficulties in the comparison, as they are akin but not alike. Disability studies, however, use approaches of meaning to the extent that they trace processes of meaning making in lives that might not be considered meaningful by broader society. In that

connection, Chivers argues that “the field of disability studies aims to recognize the full critical and cultural potential of a disability perspective; that is, scholars studying disability see that different ways of being in the world can be sources of knowledge, satisfaction creativity, and happiness” (*The Silvering Screen* 9). This approach of reading age(ing) through the lens of disability studies provides an angle to incorporate biological, social, and cultural factors that moves away from scenarios purely defined by decline, decay, and disengagement.

The above-mentioned approaches to aging and ‘old’ age present an overview of the field of aging studies. They are all frequently discussed and are not only part of an academic discourse but also reflect the public discourses on age(ing). Although this theoretical introduction mostly focused on the representation of ‘old’ age, the basic concepts of being ‘aged by culture’ or finding meaning at any stage in life are applicable to the entire life-course. All these concepts work with the terminology of ‘old’ and ‘young’ in one way or the other. These overarching concepts of age(ing)—that is age(ing) as cultural performance, age(ing) and the process of othering, progress and decline, successful aging, and meaning throughout the life-course—will be core to my discussion of centenarians and children with progeria in the subsequent parts of this book. While all interacting with the cultural, social and biological, the approaches mentioned here appear to neglect one in favor of the other. Starting from the assumption that there is an undeniable biological reality to the aging body, besides tracing these concepts in various narratives, I will thus emphasize how the connection of the biological, cultural, and social, reimagines these concepts and provides them with increased nuance. Moreover, I intend to look at the way age itself is constructed throughout narratives of centenarians and children with progeria. Therefore, the following subchapter provides a closer look at how age itself is constructed through various subcategories.

### 1.3 The Subcategories of Age

In order to analyze the construction of age through an interplay of social, biological, and cultural mechanisms, I argue that it is necessary to subdivide age into its own subcategories. In the following section, I will therefore discuss several aspects of age that have been established by various scholars and then provide my own model of subcategories which I will implement throughout this study.

There have been numerous approaches to find out what the core ingredients of age are. Sinikka Aapola, for instance, provides a very detailed model of age as a “multidimensional social and cultural phenomenon” (330), which she subdivides into four different types of “discourses”: (1) chronological age, meaning the number of years lived, (2) physical age, meaning the aging body, (3) experiential age,

meaning one's personal age experience, and (4) symbolic age, meaning the social connotations attached to a person's stage within the life-course.

Chronological age seems to be the easiest concept to grasp. Further, physical age is clearly defined as a concept referring to the human body. Understanding the concept of experiential age, on the other hand, requires additional explanation and thus Aapola clarifies that it is "the age a person subjectively attributes to him/herself" (306). In other words, it is the age we feel which is, in turn, connected to the way we act. Accordingly, experiential age refers to a maturity level which ultimately determines the way we think and behave. Hence, certain actions (for instance learning) are associated with the 'young' mind and indicate youthfulness and opportunity. Other actions (for instance playing bingo) are associated with the 'old' mind and indicate decline. Aapola adds another aspect to experiential age: embodied age. It "refers to the experiential dimension of a person's embodiment, his/her feelings and emotions. The focus is on how a person feels in relation to his/her body and its appearance and capabilities" (307). Experiential age is not only an aspect of age that is clearly personal, it is also closely intertwined with age in a biological sense. The way a person feels about their age is presumably linked to the state of the aging body.

The last of Aapola's categories or discourses is symbolic age which describes the connotations one's age behavior has in a given society. This in itself, I argue, shows how difficult it is to clearly subdivide age into its subcategories, since all of them work together in order to create symbolic age. Hence, the way a person behaves and the way their body is lined with signs of aging creates their symbolic age. One crucial aspect that Aapola's concept makes clear, is that age(ing) is also influenced by inner perception. When speaking about age(ing), the age we feel is very important, not only to us but also to the way we behave in a public setting. Feeling 'young' might actually influence how our age is perceived in a social context.

Whereas Aapola talks about age discourses, Anita Wohlmann, working in the context of literature and film, establishes different metaphors of age. She provides her readers with a definition of each metaphor, alongside an example:

the evocation of a character's chronological age, e.g. in *Away We Go*: 'We're 34.'—the description of an external appearance that is related to age, e.g. in *My Big Fat Greek Wedding*: 'You look so old'—the mentioning of age awareness, e.g. in *Cosmopolis*: 'He felt old.'—the description of age inappropriate behavior, e.g. in *Little Children*: 'It was like suddenly being a teenager again.'—the evocation of the passing of time or a sense of temporality (being premature or belated), e.g. in *Away We Go*: 'Maybe it's just late coming to me.' (69)

Wohlmann includes outward appearance to the list of age's subcategories. This addition suggests itself because she is explicitly referring to film and therefore to visual representations. As in film, in real life, we often see people we interact with

and hence, outward appearance becomes an important aspect in the construction of age. As the looks of a person are the first thing the world encounters, this category becomes a crucial initial marker of age itself. As opposed to outward appearance, Wohlmann describes 'age awareness,' which she relates to feeling a certain age. Here, the interplay of age as a phenomenon that is influenced by a person's inner self, as well as the way they are seen from the outside becomes even clearer. It is important how a person looks in terms of age because it is the looks that will initiate a categorization process within other people. However, it is equally important how a person feels about their age. Consequently, there is a close interplay between the inner and the outer definition of age.

Wohlmann's third metaphor, 'age inappropriate behavior,' does not only describe a category of age, namely behavior, but also the fact that this behavior in terms of age can be right or wrong in a given social context: It is considered to be wrong or inappropriate to act like a teenager for a person in their thirties. Behavior associated with being a teenager would hence mark a person as odd; someone who is unable to stick to social norms and does not, as Cheryl Lay puts it 'act their age.'

A sense of temporality, Wohlmann's last metaphor, can have a twofold meaning. It can be read as referring strictly to 'being premature or belated' and would thus be very closely linked to the metaphor of behavior. Moreover, and certainly connected to this quite literal meaning, it might be related to the way in which time is perceived in the context of age. Both readings entail that something happens prematurely not because a person is actually too 'young' but because they are not ready. For instance, a well-known statement in a relationship 'I feel like we are moving too fast' does not mean that the relationship really is moving too fast but that the person uttering the statement has experienced the time as not rewarding enough in terms of establishing the relationship. Moving too fast in itself becomes a metaphor for the relation of time and experience. Ultimately, this metaphor can have historical meaning as well. It links age to a sense of time and the experiences someone has made, that is, to their personal history. Wohlmann's approach has two advantages. First, it takes into account the dualism of the self and the other when it comes to the determination of a person's age and second, it reminds us of the concept of temporality, allowing us to think about age in a broader, historical context, as well as in the sense of experienced time.

One last—and certainly most prominent—example stems from Kathleen Woodward who, in her discussion of the character Warren Schmidt from the movie *About Schmidt*, elaborates on the following subcategories of age as

biologically (his body is slack and he has slowed down), chronologically (he is 66), and socially (he is retiring). He is also represented as old culturally (everyone else in the film who is in his age bracket seems hipper and thus younger), psychologically (he feels old to himself), and statistically (as an accuracy, he is familiar with

the statistics that predict the probability of a widower dying within a certain number of years of the death of his wife). ("Performing Age" 163)

What has been called 'physical age' above is termed 'biological age' in Woodward's approach. By using the term biological, she establishes connotations not only to the immediately obvious effects aging has on the body but also to the medical aspect of aging. Biological age can further also refer to the aging process within the body and not merely to its outward effects.

Woodward ties the concept of social age to retirement and therefore to productivity. As soon as a person is retired, they do not actively contribute to the economy anymore and therefore their role within society changes, limiting the social standing and agency of a person. Interestingly, she is the only scholar distinguishing between social and cultural age. As opposed to social age, cultural age evolves in interaction with other people. In alignment with Gullette's argument of age only becoming salient when we learn that it has meaning, cultural age only exists when there are several people whose ages can be referenced to each other. In a broader sense, however, social age only becomes valid as soon as there are more people involved; as in a society. In Woodward's terminology, the internal view is called psychological age, as the age a person feels. The term 'psychological' strongly indicates the assumption of age being connected to the mind and not to the body. Here, she contradicts Aapola's concept of embodied age which, as above mentioned, indicates that the age a person feels is tied to the function of the body. This opens up the debate about what has the power to determine age. Is it the body or the mind? Or are the two influencing each other?

Lastly, Woodward mentions that a person can also age statistically. In this instance, she refers to a person's awareness of statistic realities. Statistics tell us what stage of life we are in. Statistically people get married, have children, move to a nursing home, and die at certain ages. We only have to look at these statistics in order to find out what is expected from us at our age. Even though statistics seem to be a rather objective model, like chronological age, they cannot determine what age really means. In fact, the opposite is true, the relation of age and statistics is socially constructed, or at least the pressure to act according to those statistics is.

With the above models in mind, I will now introduce my concepts for how age may be subdivided into categories in order to build an analytical tool for the discussion of extraordinary age(ing). I therefore discuss the categories of outward appearance, behavior, physical age, and institutionalized age. I have purposefully left out social or cultural age and the like as subcategories of their own, because, as I have hinted at above, all aspects of age are connected to the way a person is perceived in a society as well as dependent on cultural contexts and imaginaries. Further, I do not name chronological age as one of my categories. Even though it ties into all of them in one way or another, I would like to make an argument for

a discourse of age that is not centered around chronology. Lastly, I need to point out that I am not making a clear distinction between the way a person perceives themselves and is perceived by others through those categories. Rather, I argue that in all of the aspects both the inside and the outside work together in the sense that all the subgroups of age I mention have an aspect of both, the inner feeling *and* the public perception of age. In the following I will explain how I define the subcategories of age and outline how they affect the social, cultural, and biological construct of age.

### 1.3.1 Institutionalized Age

As mentioned above, chronology is often regarded as the most prominent factor when it comes to define age(ing). The number of years a person has lived is then given meaning through social practices, cultural imaginaries, and biological processes. Consequently, chronological age is connected to certain assumptions about a person's outward appearance, physical fitness, and behavior, cumulating in general assumptions about a person's stage in life. Van Dyk, however, argues for the arbitrariness of this concept by asking "[w]hy is it, if we start out from retirement age as many do, that a 70-year-old marathon runner should have more in common with a 90-year-old demented person than with a 50-year-old manager?" ("The Appraisal" 99). Van Dyk here questions the general category of 'old' age as defined by chronology. Yet, her inquiry is applicable to all life stages. Why should the number of years a person has spent on this planet indicate significant attributes of their lives?

In order to avoid building my argument around what Kunow calls a "seemingly 'objective'" measurement of life ("Chronologically Gifted" 23), I would like to shift the focus to institutionalized age, as the concept of age that is formed through institutions. Obviously, chronological age itself is institutionalized through birth certificates and the celebration of birthdays, however, there is much more to that institutionalization of age than just a number. Rather, chronology is a minor part of institutionalized age, as it is institutions that make chronology possible in the first place. Institutions form the life-course and whatever institutional phase a person is in, generates assumptions about their age. The education system, for example, is built in a way that students are sorted primarily by age and not by abilities. It is commonly known that in the U.S. a child is to start Kindergarten when it is five years old and graduate from high school at the age of seventeen or eighteen. If students are older than that, it is clear that they have been held back, meaning that they were not able to fulfill the requirements that all the other kids in the arbitrary category of 'the same age' supposedly have. Age therefore can very early become a stigma through institutions. Consequently, the institutionalization of the aging process, restricts the occurrence of alternative temporalities.



Institutionalized age, more than all other categories of age, generates assumptions about a person's abilities at a given point in time. By restricting the right to vote in the U.S to people eighteen and older, there is the implicit assumption that as soon as their eighteenth birthday arrives, people have developed a political consciousness that allows them to make informed decisions about the nation's government. To put it bluntly, a person who turns eighteen one day after an election is not expected to have that same maturity. The same goes for the criminal justice system where age can become a determining factor on the decision of whether a person has to take full responsibility for a committed crime. In that connection Corinne Field and Nicholas Syrett argue that distinctions based on age "have been necessary, for lawmakers especially, as a means of appropriating legal incapacity and responsibility in a way that has seemed logical and all-encompassing, if not always equal and fair. But they have also been arbitrary in that the same lawmakers could have selected a different perhaps proximate age for marking their legal distinctions" (2). Even though, chronological age seems to appear a fair marker for legal purposes, its institutionalization into lawmaking shows that it is often connected to arbitrary decisions.

Institutionalized age does not only influence the early years of a life, even though most of the institutional milestones (starting school, being allowed to drive, etc.) take place at a 'young' age. For 'old' age, especially the institution of retirement becomes important. Through the Social Security Act of 1935, retirement with full benefits in the United States was made possible at age 65 and thus

[s]ixty-five has become ingrained in people's expectations. It has become the normal retirement age at which full benefits are paid under Social Security and the great majority of private pension plans. It is very possible that, as workers draw close to 65, they begin to feel the need to stop working full time, quite apart from the effect of the aging process itself. ("Retirement Age"121)

Consequently, institutions determine the time when individuals deem it appropriate to retire, often influencing individual decision making. This leads to the common assumption that 'old' age begins at the age of 65 (Achenbaum, "Delineating Old Age" 301), an assumption that is highly influenced by the institutionalization of age.

Institutionalized age is thus not only connected to chronological age but also to what Woodward calls the social aspect of age. Through the implementation within institutions, life stages become graspable, which makes institutionalized age an important component of age as a concept. Ultimately, it is important to bear in mind that the way age is implemented into institutions is rather arbitrary. Western societies, and especially their definition of what 'old' age is, for instance, would most likely look different if mandatory retirement age had always been at eighty. When considering institutionalized age, it is crucial to remember that it is precisely

not 'just a number,' but a network of rules and privileges that are institutionally tied to this number, structuring the life-course.

### 1.3.2 Outward Age

The definition of outward appearance is fairly simple: it refers to the way a person looks. When it comes to appearance in terms of age, certain features become more important than others. For example, the relevant distinction between hair colors is not brown-haired versus blond, it is any color versus grey or white. Other obvious signs of 'old' age include wrinkles and age spots whereas signs of 'young' age, especially during the teenage years are symptoms like acne. As Margaret Gullette puts it, "the external signs of aging . . . do not usually cause physical discomfort nor seriously affect bodily functions" (*Aged by Culture* 9). Accordingly, I am at this point merely referring to those aspects that meet the eye and instantly inspire assumptions about age. This category is in the above models only explicitly addressed in Wohlmann's metaphor of external appearance. The other models frame outward age, if they mention it at all, as a part of physical or biological age. Whereas that is certainly a valid categorization since outward age is determined through the aging body, I argue that outward appearance plays such a prominent role in the determination of age that it needs to be regarded as an entity of its own.

Because the outward appearance or the outward age of a person is the first thing we notice when meeting someone, it serves as the initial defining category of age. Accordingly, looking at a person can assumingly give a more or less accurate indication of their age. This presuming gaze entails a great deal of social influence: If people like to spend time with people 'their own age,' an outward age not matching their own can keep them from getting to know their peers. Consequently, there is the social pressure to look the way members of our society would assume someone our age to look like. In that sense, the statement 'you don't look your age' can be an insult or a compliment, but it is always exclusive, since, by not looking their age, people are prone to being excluded from their own age group.

As we get older, however, the wish to determine age by looks is often replaced by the opposite: We do everything possible to *not* look our age. Whereas for instance in a university context, older students try very hard not to look 'young' enough to be mistaken for freshmen and to be instantly recognized by their own age peers, at some point that desire shifts into a desire to look younger. This goes along the lines of Gullette's claim that people need to attempt to remain part of a progress narrative. At a certain point in life, trying to look 'young' becomes necessary in order to escape decline and to, as Katz puts it 'grow older without aging.' Hence, people start using 'anti-aging' products in order to halt the outward aging process. Here, outward age is the subcategory of age that directly connects to the consumer market established for those who try to age agelessly.

Moreover, reaching a certain age is associated with losing attractiveness and fertility. As Susan Sontag describes in her essay “The Double Standard of Aging,” this is especially destructive for women whose role entails to appeal to the other sex and bear children. She writes that “[w]omen become sexually ineligible much earlier than men do” (31), meaning that women lose their sexual appeal to men at a comparably early life stage. In addition to the ability to bear children, this loss of attractiveness, as subjective as it might be, is also determined by the outward age of a person. As Toni Clasanti and Kathleen Slevin point put,

increasing numbers of people spend hours at the gym, undergo cosmetic surgery, and use lotions, creams, and hair dyes to erase the physical markers of age. Such is the equation of ‘old’ age with disease and physical and mental decline that visible signs of aging serve to justify limitation of the rights and authority of old people. (8)

In other words, looking ‘old’ deprives a person of social status and therefore people work very hard to appear ‘young.’ In this connection, outward appearance has a tremendous influence on the way age is socially constructed, while social construction as well as the cultural representations and imaginaries tied to it, in turn, influences the beauty ideal of a society. Only because ‘old’ age is associated with decline and death, it becomes socially important to look a ‘young.’ Hence, people try very hard to look ‘young’ and those who cannot or just will not join the normative expectation of this outward illusion, are perceived as disengaged from society.

Outward age then categorizes our life by means of giving others the opportunity to make instant assumptions about our age. Since Western societies associate attractiveness and vitality to the ‘young,’ anti-aging products become a tool to remain a member of this group. Keeping the discussion of ageism and disengagement in mind, outward age can instantly put a person into a social position of isolation. Hence, the outward age of a person in itself bears social significance as it determines our first impression of other people.

### 1.3.3 Behavioral Age

Behavior in itself is a broad term. According to the OED, the basic definition of behavior is the “[m]anner of conducting oneself in the external relations of life; demeanour, deportment, bearing, manners.” When it comes to age(ing), there is a certain manner expected from a person in external relations. By behavioral age, I thus mean specific behavior that derives from a person’s maturity level. This definition is inspired by a statement of James Holstein and Jaber Gubrium who explain that “an individual’s life course is made up of the roles he or she may occupy over time” (339). These roles are to be filled in a certain manner and with certain expectations tied to them. As a teenager, for example, an individual is allowed to behave

reckless to some extent. If a person in their mid-thirties behaved in a similar fashion, it would go against the requirements of the role in the life-course a person is expected to play at that age. Behavior, hence, is also tied to Gullette's concept of 'life-course imaginaries.' The imagined life-course is enacted through changing roles an individual occupies over time.

One part of behavioral age is determined by a person's likes and dislikes, the books they read or the films they watch. Movies and literature are, for example categorized in terms of age. There are, on the one hand, those pieces that are forbidden for younger people and on the other hand there are books and films that are specially labeled for children, teenagers, or 'young' adults. What happens then, if a fifty-year-old excessively reads young-adult-literature? How are they are perceived by other fifty-year-olds? Does the act of reading a book, watching a film, or listening to a certain kind of music imply that much about our persona that we might become an outcast of our very own peer group of age? These questions are playfully navigated in the U.S. American TV show *Parks and Recreation* where a middle-aged man is a big fan of the *Twilight* saga ("The Capsule"). His interest in the books, which can clearly be defined as young adult literature and as mostly marketed to female readers, makes him a strange character and an outsider within the episode. For the audience on the other hand, he is a joke but certainly nobody that would be described as acting 'normal.'<sup>4</sup> Through his age inappropriate interests, the character is thus moved to the margins of society.

As opposed to the individual's ability to act according to or against the conventions of age, a person's behavior can also be influenced by the way they are treated by others. In that connection, Holstein and Gubrium elaborate that "[s]elf-conceptions generally involve notions of age and life stages. Interacting parties construct the meaning of experience with reference to the temporal dimensions of others' definitions. For example, if a child senses others beginning to treat them as 'teenager', then he or she is likely to assume a teenage identity" (339). The roles people play age-wise are thus not only determined by the way they feel but, to a large extent, by the way they are treated by others. Here, the interplay between the outside and the inside measures of age construction becomes obvious again. Besides the socially constructed sanctions of being marked as the 'other' when not acting age appropriately, there is also the construction of the age appropriate behavior itself. As soon as the surroundings of a child decide that they are now a teenager, the treatment of that child will change accordingly. The child, knowing that the social expectations for behavior have changed, in turn accepts the new role and starts to act as a teenager in order to avoid the above-mentioned social sanctions.

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4 In this case the inappropriate behavior concerning his age and the inappropriate behavior concerning his gender work together in presenting his character as the odd one out.

The concept of behavioral age thus combines aspects of age inappropriate behavior (Wohlmann), experiential age (Aapola), and psychological age (Woodward).

For the discussion of 'old' age these findings suggest that there is appropriate behavior connected to this stage of life as well. Since cultural assumptions of decline and disengagement are prevalent in Western societies, it is expected that an 'old' person exists and behaves outside of mainstream society. These expectations are quite nicely summed up in another example taken from popular culture: *How I Met Your Mother*. In the episode "Murtaugh," protagonist Ted Mosby explains that there are some things that he is too 'old' to do, for example vandalizing the local laser tag facility with toilet paper. Further, he explains that he cannot wait to be 'old' because "life is a meal and old age is the dessert" (08:16). His friends bet him that he is not prepared to live according to a list of things they assume 'old' people do. This list includes yelling at neighborhood kids, having dinner at four o'clock, going to bed at eight o'clock, getting up at four o'clock in the morning, and taking forever to answer the phone.

To yell at neighborhood kids stands for the assumption that 'old' people are grumpy and set in their ways, which restricts them from understanding younger generations. As they are deemed unfriendly and unable to understand the ways of the 'youth,' they can never be a part of their society. The list thus indicates that behavior expected from the 'old' truly is behavior that fosters isolation. This is made even clearer through the daily routine mentioned in the list. Apparently, 'old' people have a fundamentally different daily schedule that is not compatible with those of the 'young.' It becomes therefore impossible for 'old' and 'young' to interact. The last nail in the coffin of isolation is the assumption that elderly people are too slow. Taking forever to answer the phone does not only mean that most people would hang up by the time the called person even reaches the phone. Even more, it implies that getting in touch with 'old' people is almost impossible because they simply do not respond. Lastly, the assumption of slowness serves as an example for many instances in daily life where 'old' people are thought to be too slow to participate in the actions of the rest of society. *How I Met Your Mother* illustrates that the expectations of 'old' behavior are closely tied to disengagement, isolation, and loss of power. Especially since Ted Mosby is, in the beginning, eager to live according to the conventions of an 'old' man and then, after doing it for a while, decides to "screw being old" and to "go TP laser tag" (17:26), the lives of the elderly are denounced. Consequently, behaving like an 'old' person is depicted as something that nobody in their right mind would want to do.

The assumptions *How I Met Your Mother's* characters make about age, make clear that as soon as someone is 'old' the need to act age appropriate reversed into the opposite. It becomes unwise to act in a way that confirms one's 'old' age because that behavior would move a person to the margins of society. In that connection Rüdiger Kunow argues that "only when the elderly present themselves as not old,

preferably by behaving like everybody else, can they hope to attain a public voice and public presence” (“Postcolonial Theory” 104). Therefore, in ‘old’ age, people need to either alter their behavior and act ‘young’ or they lose their social agency. At the same time, children or teenagers often try to act older to be perceived as more mature and earn more privileges, again indicating the middle-aged as the dominant group, setting the tone for behavior that will earn an individual social participation. Conversely, one could argue that behavior assigned to ‘old’ age determines when someone is ‘old.’ That would mean that only by sticking to the behavioral catalogue of the elderly, a person can truly become socially ‘old.’ At the same time, as Charyl Lay points out in her article of the same title, it is important to “Act Your Age,” as deviating from expectations too far is also socially sanctioned. It is thus a fine line of behaving ‘young’ enough to be considered not ‘old’ but, at the same time, to still stick to behavioral codes that do not stray too far from one’s other age categories.

### 1.3.4 Physical Age

The category of physical age describes the activities or fitness level expected from individuals based on their body’s age. A child, for instance, is expected to take their first steps around the age of one. ‘Young’ adults are supposed to be at the height of their bodily fitness and show it within their everyday life. They go out to dance, do sports, and are able to lift heavy things without hurting their backs. In later life, instead of dancing and running, people are expected to develop a limp, get a hip replacement, and walk slowly. The assumption that ‘old’ people are not as fit as ‘young’ people plays a major part in the discrimination of the elderly population because it is closely linked to a loss of independence. In this sense, physical age is also connected to the medicalization of age. The aging body, through biological processes, does get weaker over time. Therefore, it is often defined by its medical conditions. This is mirrored in the answers sociologist Charyl Laz receives when asking elderly people about the meaning of age:

My eyesight. My eyebrows and eyelashes. My gallbladder problem. My weight. My energy level. My legs. My wrinkles. My hearing. My stiff joints. My arthritis. These are among the things participants in a study refer to when asked to talk about age. . . . the frequency with which respondents focus on bodies, body parts, and physical abilities and activities is striking. (“Age Embodied” 503)

In these statements it becomes clear that for many people physicality and especially medical problems are the defining factors of their age. Further, Laz’s interviewees suggest that outward age ties into the construction of age as well. Nevertheless, most aspects mentioned are connected to the medical state of the body which often leads to a state of isolation. A lack of hearing, for instance, does not hinder someone to take part in actions that are reserved for the ‘young’—a person with

bad hearing is still able to surf or skateboard—it does however impair the opportunity of interaction with others. Losing the ability to hear, and the same goes for the loss of all other senses, means social interaction becomes more difficult and can thus lead to isolation. Stiff joints, on the other hand, are medical conditions that have a larger effect on the activities a person is able to pursue. Laz's interviews show that age(ing) is strongly medicalized. When asked about age, older people are inclined to refer to the things they cannot do and to the problems their body has. Is one, conversely, only truly 'old' when the body has acquired medical conditions that are associated with 'old' age?

In this instance the link between 'old' age and disability becomes apparent. If being 'old' is determined by the loss of the physical ability to do certain things, 'old' age would be a disability. And yet, as Sharon-Dale Stone points out "when confronted with a young person who is clearly disabled, we are primed to understand that person as a tragic exception to the rule that young people are able-bodied" (63). It is thus not only bodily dysfunction that isolates the 'old.' There is a strict distinction made between having a disability and having an age-related disability. In times of positive aging and neoliberalism, there is a general distinction made between disabilities that cannot be tied to a certain behavior and disabilities that can. People whose legs were amputated due to years of chain smoking will more likely face social push back than those who lost their legs in a car accident caused by a drunk driver. The same goes for 'old' age. Successful aging paradigms suggest that it is possible to stay healthy until a high age and whoever does not manage to do so deserves to be an outcast. Further, Chivers argues that "in the public imagination, disability exists separate from old age, but old age does not ever escape the stigma and restraints imposed upon disability" (*The Silvering Screen* 8). In other words, a disabled person is never imagined in their later years, whereas an 'old' person is always imagined as disabled and stigmatized as such. The disability of an 'old' person, however, is regarded as an age-related disability. People who age with a disability are therefore invisible to the public. Conversely, if a bodily dysfunction presents itself in 'old' age, it is assumed that 'old' age itself is the disability.<sup>5</sup>

Physical age describes the abilities and expectations of a body in connection to its age. It is thus connected with Woodward's concept of biological age, as well as Aapolas discourse of embodied age. Especially the connection to Aapola is crucial here because she acknowledges how the abilities of the body also have the power to shape a person's age awareness. Having stiff joints and arthritis can lead to a

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5 Connected to the discourse on physical ability and independence is the loss of brain function. Dementia is regarded here as a part of physical aging. However, dementia is not the focus of my discussion, rather, I will be discussing the narrative structures that emphasize the absence of dementia and thereby indicate that age related conditions of the mind may be harder to live with than those of the body.

feeling of ‘oldness’ within an individual and manifest a self-classification thereof. Conversely, a person moving with stiff joints invites the assumption that this person is categorized as ‘old.’

### 1.3.5 The Jigsaw Puzzle of Age

In her discussion of age, Anita Wohlmann claims that it is “a lens through which we have learned to assess people. It has become a crucial social category, similar to class, race, and gender, which classifies and describes individuals” (41). After looking at the subdivision of age into four categories, I would like to suggest that age is actually not one, but four lenses through which we assess people. These four lenses are in constant communication with one-another and cannot always be clearly distinguished. Usually, the aspects of all four categories align with each other. Cheryl Laz points out that “[a]lthough age often feels like something we simply are, it feels this way because we enact age in all interactions. Since we usually act our age in predictable ways—predictable given a particular context—we make age invisible. We make it *seem* natural” (“Act Your Age” 100). Consequently, if we perform age right or, in other words, if we stick to the normative assumptions connected to it, and do so in all aspects of age, it is naturalized.

If age can be made invisible by meeting the normative assumptions tied to it, the question reveals itself, whether it, and especially its construction, becomes visible when the four above mentioned categories do not align and age is therefore not naturalized. In the course of my analysis, I will argue that individual categories can become visible in certain contexts and dominate the determination of a person’s age. Sociologist Stefan Hirschauer argues that categories of human differentiation mutually influence each other. He elaborates that “some differentiations get in each other’s way, others meet without consequences, some reinforce each other, others neutralize each other” (185, my translation).<sup>6</sup> Hence, different categories may reinforce or weaken each other depending on the context. Since age is in itself subdivided, I am interested in the ways these subcategories influence each other and, ultimately, how they contribute to the construction of age in general. I therefore regard age as a jigsaw puzzle, whose parts may be shuffled. Only one image is perceived as ‘natural’ but moving the pieces around may help us understand the construction and the meaning of the puzzle as a whole.

Since, according to Laz, in cases in which people act ‘right’ age is invisible, I have chosen examples of age(ing) that challenge the alinement of the subcategories of age. In the following, I will elaborate on my choice of centenarians and children

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6 The original German text reads as such: “[m]anche Differenzierungen kommen sich in die Quere, andere begegnen sich folgenlos, manche verstärken sich gegenseitig, andere neutralisieren sich” (185).



with progeria as examples of extraordinary forms of age(ing). These examples rearrange the jigsaw puzzle of age in an unexpected fashion and allow us to renegotiate its construction and meaning in terms of the individual subcategories.

## 1.4 Extraordinary Forms of Aging

The way we think and speak about age(ing) is deeply rooted in Western societies. Consequently, Mita Banerjee and Norbert Paul argue that “[i]n order to overcome the established rhetorics of aging, we are in need of ‘wake-up calls’” (271). Forms of age(ing) that are not what Charyl Laz would call naturalized can serve as those wake-up calls and make us aware of the construction of age, and the rhetoric that encourages age discrimination. Moreover, these wake-up calls encourage us to reevaluate binary concepts of age(ing) as progress and decline or successful and failed, and ultimately allow for a discussion of age(ing) in light of the interplay between the social, cultural, and biological in order to offer alternative ways in which age(ing) can be performed. These wake-up calls are forms of age(ing) that are extraordinary in the sense that they undermine the alinement of the above discussed subcategories and/or go beyond what would be considered the norm. Thomas Cole, for instance mentions ancient notions of such disruptions and explains that “a rare child (a *puer senex* or *puella seneca*) might possess the wisdom and virtue that could not ordinarily develop in the natural order until ‘old’ age. Or an older person might display the virtues of *infantia spiritualis*, the simplicity and purity of a small child” (7-8). These are examples of behavioral age being out of touch with the other subcategories, creating a curious phenomenon.

In this study, I will discuss three examples of life narratives of centenarians and children with progeria each in order to understand how their position at the intersection of the normative and the non-normative as well as the cultural, the social, and the biological contribute to the broader understanding of the aging process. On a topical level, all narratives share common themes. They all deal with (dis)ability and care, (aging) lifestyles, ‘old’ age as a disease, and processes of overcoming negative age(ing) imaginaries. The examples I have chosen challenge the subcategories of age as well as notions of aging temporalities in general. On the one hand, centenarians have the ultimately stretched lifespan, whereas the age-acceleration of children with progeria leads to a very compromised life expectancy, resulting in very different approach of time and experience. I will in the following briefly outline how the chosen examples can shed new light on the debates surrounding age(ing).

Centenarians are considered the stars of aging. A growing body of literature about centenarians has two major purposes. First, people who have experienced an entire century seem to have a tremendous historical value. Therefore, one fas-

ination with centenarians is that they are what is called “Zeitzeugen” in German, people who have lived through a certain period of time and can give a first-hand account of it. Centenarians, due to their extraordinary ‘old’ age, have lived through a very large time span and can therefore give accounts of times, nobody else can remember. A good example of this historical fascination is Emma Morano from Italy. In 2016, she was the only known person to be alive on this planet who was born in the 19<sup>th</sup> century. She has become an international phenomenon because of her age and the historic times she has lived through (Diepes). A BBC article concerning her 117th birthday, for instance, opens with “[w]hen Emma Morano was born, Umberto I was still reigning over Italy, Fiat had only just been established and Milan Football Club was still a few weeks off creation” (“World’s Oldest Person”). It is thus the fascination with all the changes she has seen throughout her lifetime that make her worthy of being reported on.

The second aspect, which is featured in many articles reporting on centenarians, is a section about the centenarian’s lifestyle which, presumably, lead to an exceptionally long life. In Emma Morano’s case a large part of the articles written about her are dedicated to her diet of “raw eggs and biscuits” (“World’s Oldest Person”). This focus on the ‘secrets of longevity’ stems from the fact that centenarians have achieved what so many want: to live a long life and to be, according to the news coverage on the topic, still able to interact with the rest of the world. In that connection, Gullette claims that “longevity appears to promise that there will be *more* time for using our midlife powers” (*Aged by Culture* 31). It is thus implied that who lives longest, gets the most ‘good’ years in life. Accordingly, there appears to be a public interest in the question of how centenarians managed to live to their extraordinary ‘old’ age. Their narratives, in this regard, become guidebooks for longevity. Therefore, as soon as a person has become a centenarian the social connotations of age seem to change. In fact, Christine Overall argues that

Media accounts of very old people often, rightly, treat extreme old age, especially if the individual is still fairly healthy, as an accomplishment, on the grounds that it may take a certain kind of character or perhaps particular choices, efforts, and ways of life to live for a long time. But, once again, what is valued is not sheer temporal endurance itself but rather something that is connected to that endurance, in this case, the living of life in exemplary way. (97)

Centenarians have thus accomplished the highest goal of human existence: They have managed to age well enough to overcome the social isolation believed to be inextricably linked to ‘old’ age. Since they are expected to be able to tell the broader public about history and are therefore expected to have a working memory, centenarians have to be regarded as a part of society. Centenarians, in their role as the stars of aging, become role models for positive aging which in turn means that they can never have reached the stage of decline and disengagement; they have

never been put into the 'waiting room' of 'old' age. Consequently, the social construction of 'centenarianness' in public discourse questions the social construction of all other age groups by turning the meaning of the subcategories of age and the expectations tied to them upside down.

Progeria<sup>7</sup>, on the other hand, can in certain ways be regarded as the opposite of 'centenarianness.' Children with progeria have an extremely shortened lifespan due to their condition. Even though their life expectancy is only about 13 years, part of their bodies, at that time in their lives, is biologically comparable to that of a centenarian in many ways. Children with progeria are an example of the complete juxtaposition of different age categories. In that sense, I am especially interested what the fact that a 'young' mind lives in an 'old' body does to the concept of age(ing). Further, children with progeria are the opposite to centenarians when it comes to the temporality of life. Whereas centenarians have to ask themselves what they do with their extra years, children with progeria have the difficult task to, in Ricca Edmondson's terminology, make a life meaningful that will only last a very short time.

Besides upsetting the alignment of the subcategories of age and giving insight to the creation of the life-course in terms of meaning, discussing narratives of progeria can help to understand the interplay between 'old' age and disability or illness because in this special case, 'old' age really is an illness. In line with Chivers' approach to look at 'old' age through the lens of disability studies, progeria narratives force the audience to regard the aging body in terms of disease and disability. In that sense, discussing narratives of progeria can serve as a point of inquiry for the redefinition of 'old' age through the lens of disability studies by not only sparking a discussion of disability in 'old' age but also changing the rhetoric of age(ing) towards value and knowledge. Moreover, progeria narratives offer a unique chance to look at age(ing) without the pitfall of successful aging at hand. The condition makes it abundantly clear that these children will not age successfully. While the paradigm is absent from these narratives, they present ways to find meaning and happiness within their aging process without having to perform successful aging.

Even though the cases of centenarians and children with progeria are very different from each other, both extraordinary forms of aging can serve as wake-up calls to renegotiate the rhetoric of aging. Both are conditions that realign the subcategories of age and occasionally even completely juxtapose them. Therefore, they make age(ing) visible through its denaturalization. This denaturalization, in both cases, leads to a commercialization of the cases. Centenarians, as well as children with progeria do not simply exist but they are, to use Luce Irigaray's terminology

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7 The narratives I discuss are all about children with Hutchinson-Gilford progeria syndrome which is the most common form of the disease. I will use the term progeria to refer to Hutchinson-Gilford progeria syndrome.

“fabricated” (802). In both cases, individuals are turned into phenomena that in effect become sellable narratives or, in Marxist terms, commodities. I am not conducting a Marxist or Feminist reading of these narratives of extraordinary age(ing), nevertheless, I am applying Irigaray’s idea of women as commodities, fabricated by men, to narratives of extraordinary age(ing) in order to reveal the processes of how age is (re)negotiated and constructed or fabricated in a society that emphasizes economic worth in an individual. Irigaray argues that “[a]s commodities, women are thus two things at once: utilitarian objects and bearers of value” (802). Moreover, Irigaray elaborates that “a commodity has no mirror it can use to reflect itself” and women therefore “serve as a reflection, as image of and for men” (808). If extraordinary age(ing) becomes a fabricated commodity, it becomes an object of value and, at the same time a reflection of what society needs it to be. As women, according to Irigaray, reflect male desires, I argue throughout this book, that narratives of extraordinary age reflect a broader social desire to live long and healthy lives. What is the role of the individual in this social network? How do economic factors tie into the construction of extraordinary age(ing) in particular and age(ing) in general? And how does the phenomenon of being a centenarian or a child with progeria heighten a person’s visibility? I am interested what this new visibility of denaturalized age(ing) can contribute to the field of aging studies and the discussion of the construction of age.

## 1.5 Extraordinary Age(ing) and Life Writing

In relation to the above mentioned argument that wake-up calls can serve as means to understand and change the rhetoric of ‘old’ age, Charyl Laz explains that “[s]ociologists can study disruptions of ‘the normal,’ like the ‘clicks’ [moments in which you are suddenly aware of your age] described above, to explore how normalcy is accomplished, how the ‘natural’ *becomes* natural” (“Act Your Age” 101). I argue that these ‘clicks’ can be traced within the life narratives of extraordinary age(ing) and that these biographical works can serve as a starting point for the analysis of age(ing) in general.

I am referring to life narratives in the broadest possible sense of the concept as a medium to find out how age(ing) is discussed through the extraordinary cases of centenarians and children with progeria. I am not only looking at full length (auto)biographies but also at *YouTube* videos and documentaries. I use the notation ‘(auto)biography’ for two reasons: first of all, all the narratives discussed here are forms of life writing but not strictly autobiographical. Philip Lejeune defines the characteristics of autobiography by establishing the concept of the “autobiographical pact” (86). One main part of this pact is the idea that “[a]utobiography (narrative recounting the life of the author) supposes that there is *identity of name*

between the author (such as s/he figures, by name, on the cover), the narrator of the story and the character who is being talked about" (91). This definition of autobiography is not met in the narratives discussed in this study. For one, I am looking at documentaries and stories that are produced about or in collaboration with the extraordinary agers. That is, many of the texts in my discussions would fall under the definition of biography rather than autobiography. Secondly, even those texts which are marketed as full-length autobiographies are collaborations between an author and a co-author, disqualifying them as autobiographies in the sense of Lejeune's autobiographical pact. The mechanisms of these collaborations will be discussed further throughout this book. In this current section, I would like to discuss how studying life narratives can contribute to an understanding of the processes connected to the construction of age at the intersection of the social, the cultural, and the biological.

Auto/biography, as Alfred Hornung points out, "may mediate between individual positions and choices taken in life, in the sense of the critical concept of relational selves . . . , or they may mediate between self and place, as in imaginary geographies and eco-biographies" (xii). If auto/biographical texts can thus function as a mediator between different positions, and even serve to negotiate one's own identity, I argue that they can also function as a mediator between different life stages, as well as a platform for the inner negotiation of an age(ing) identity. What does it mean to be a centenarian, and what does it mean to be a child with progeria? How do people define themselves in relation to their extraordinary age(ing)? What categories of age become important within these negotiations? And: How do they convey this age(ing) identity to the outside world? Further, life narratives can serve to mediate the inside and the outside; meaning, the way a person perceives themselves, the way they are perceived by others, and the reciprocity between the two. Here, the form of collaborative life writing seems especially fruitful as it not only provides the perspective of the aged individual but also, read against the grain, the perspective of the collaborators who are usually middle-aged. As I am pointing out throughout this study, these narratives are entrenched with moments of younger generations renegotiating derogatory imaginaries of age(ing) and illness. This may be connected to a desire to portray age(ing) in a way that makes it alluring to be 'old' in order to envision 'old' age as more appealing.

Narrating one's life can in itself be a meaning giving instance. By retelling their life's story, people can make sense of their past, and the person they have become. In that connection, Stephen Katz points out that "[n]arrative gerontologists . . . show that narratives are more than just biographical stories: they are practices that connect the contents of stories and the circumstances of storytelling to the art of rendering lives coherent and meaningful" (*Cultural Aging* 132). Narratives are means to make sense of the past and, likewise, make sense of the aging process. The story of one's life then becomes the attempt to give meaning to one's own life-

course. Disentangling this attempt can give clues about the cultural image of the aging process as experienced by the aging individual.

If we want to explore how a life at any stage becomes meaningful, it is crucial to discuss life narratives. Of course, we have to bear in mind that a life narrative is created in a certain phase in life which might influence the question of what is meaningful and important and what is not. Ricca Edmondson points out that meaning is not only determined culturally but also temporally. She explains that “words and sentences mean different things in different contexts” (201) and thus, the meaning of age(ing) is different in different context. What a certain life stage means to a person and what it consists of is dependent on the cultural context this person lives in as well as the stage in life they currently find themselves in. For a child, for instance, often everybody over the age of twenty appears to be ‘old,’ whereas a 70-year-old might still consider themselves ‘young.’ Further, for a toddler, meaning in life may be given foremost through familial relationships, the 70-year-old on the other hand might feel that family relations alone are not enough to give meaning to an existence. Ultimately, life narrative can give a first-hand reading of the effects extraordinary age(ing) has on a life. At the same time, we have to bear in mind that these accounts are subjective and specific to the circumstances they evolved in. The great promise of using life narrative in the discussion of age(ing) lies in the concept of changing perceptions. Because identity changes over time and because our views on age(ing) constantly do the same, we need these first-hand accounts in order to understand the complexities of aging.

The perspective on a certain issue does not only change throughout time, it also depends on the general socio-cultural background, as well as other categories of difference such as an individual’s race, class or gender. As mentioned above, women, for instance, can expect to have to face ageism earlier than men. Similarly, in the Western world, ethnic minorities face “higher levels of disadvantages, inequalities and exclusions . . . into old age compared with the dominant White ethnic majorities” (Zubair and Morris 900). Those groups who face discrimination throughout life, are thus also faced with more obstacles in ‘old’ age. This does not only apply to race or gender but also to class or illness, among others. The examples I discuss here are taken from different cultural and national backgrounds and present people with different races, classes, genders, and even nationalities. While the focus remains on the aging process in general, my analysis will also show how different contexts influence this process as a whole as well as an individual’s attitude towards it, may it be in a biological, social, or in a cultural sense. Looking at life narratives and lived experience offers an entry point to a variety of perspectives on age(ing) within different social and cultural contexts. Consequently, the analysis of life writing encourages an intersectional approach, concerning the way age(ing) is influenced by other categories of difference.

Narratives of centenarians and children with progeria convey their perspective on age(ing) and meaningfulness and allow their audience to see how extraordinary age(ing) is negotiated at the intersection of culture, society, and biology. Those (auto)biographical works hence have the power to act as counter narratives to the dominant discourses of ‘old’ age. Laculle and Baars claim that “[b]y providing alternative stories challenging the damaging identification with oppressive master narratives, a counter narrative can empower the concerning social group, generate respect and social value for the people belonging to it” (37). If extraordinary forms of age(ing) can be used to gain insight into normative processes of aging, those accounts can also be seen as a counter narrative working to disrupt negative stereotypes of ‘old’ age in general.

Besides offering insight to the way age(ing) is negotiated socially, culturally, and biologically, narratives of extraordinary age(ing) can also be analyzed from the angle of life writing in general. As collaborative forms of narrative, they provide the opportunity to rethink age(ing) from different perspectives. At the same time, the means of production encourage a closer inquiry into questions of agency and voice within these stories. It is crucial to note that the narratives discussed here are examples of different forms of collaboration. I look at co-authored (auto)biographies in which the co-author functions as the person who edits and structures the narrative, as well as documentaries and *YouTube* videos in which directors stage a certain storyline. There have been several scholarly approaches on how to deal with collaborative life writing. Craig Howes, for instance, trusts the sense of the editor to not alter crucial parts of the narrative. He argues that although editors work with the text, consult secondary sources, and make alterations, “they also know that a text has its own integrity, and too much research could undermine their work” (5). Howes trusts the work ethics of the editors and assumes that they try to remain true to the voice of the autobiographer. The same would then be assumed for co-authors or ghost writers.

Howes’ elaboration follows similar lines as G. Thomas Couser’s argument in his monograph *Vulnerable Subjects: The Ethics of Life Writing*. He explains that whenever someone writes the story of their own life, it is inevitable that the lives of others will be part of the narrative, which makes them vulnerable to the author. Moreover, Couser claims that those whose lives are written about by co-authors or ghost writers, stand in the same position of vulnerability. He especially refers to those who through disability or illness are unable to narrate their own lives (x-xi). Apparently, centenarians and children with progeria are assumed to be unable to write down their life histories themselves, too, presuming that they are in need of the assistance of co-authors, directors, or producers. Yet, we do not know the extent to which the collaborators have been part of the production—and to which extent their voice influences the narrative as a whole.

While it is never certain if an editor or co-author was true to the ethics of life writing, we also have to bear in mind that these stories may have never been written without the initiative of the collaborators. In that connection Mita Banerjee and myself argue that in regard to relational autonomy “[t]he possible loss of narrative authority may be compensated by the fact that the life story of a centenarian would otherwise not have been written in the first place” (2). The same would apply to narratives of children with progeria. When reading life narratives of extraordinary age(ing), it is thus important to also look at the means of production and question how they may have been influenced through the voices of the collaborators. Consequently, the question of agency and the way age is culturally constructed through different voices within one narrative will be a main focal point of this book. Despite the question of ethics, I see these collaborations as a chance to trace different perspectives within one narrative. I am precisely interested in reading individual scenes through these perspectives, that is, reading them with and against the grain. In that connection, I am also interested in the extent to which life narratives of extraordinary age(ing) align with public discourses of age(ing) in general.

Moreover, narratives of extraordinary age(ing) raise questions of the commodification of age(ing) and disease, or the commodification of individuals in general. As wake-up calls, these aging processes do not only serve for a scholarly analysis, they also generate public interest by simply portraying processes situated outside of a supposed norm. It suggests itself to see centenarians and children with progeria not only as an active part of consumer markets but also as products that are put on this market. At the same time, if the image of ‘old’ age is tied to a neoliberal sense of economic worth, what happens if the aged become authors or participate in a documentary, thereby contributing to the economic processes?

Depending on the angle they are perceived from, narratives of extraordinary age(ing) are contradictory in themselves. What they ultimately show is the complexity of the aging process, and the difficulty to untangle perspectives, experiences, and finally the social, biological, and cultural framings in order to get a better understanding of how age works in society. Reading these narratives, as well as their modes of production, against the grain often reveals the wishful thinking of younger generations who want to imagine the aging body in a certain way. Successful aging becomes not only a neoliberal paradigm for the ‘old’ but is revealed as a goal that people who fear ‘old’ age wish to achieve. In that sense, the narratives at hand share the underlying cultural wish to live forever. Accordingly, all these narratives deal with the quest to live as long and as healthy as possible, presenting living longer as an achievement. Conclusively, there appears to be an underlying wish to live longer than others, turning the aging process into a competition. With this focus, it seems that an individual’s happiness or way of life is demoted to second-



rank. In fact, happiness in these narratives often comes across as a justification to extend life even further.

In a broader sense that goes beyond the mere discussion of age(ing), these narratives reveal an ever-present desire for perfection, a desire to win and be better than everyone else—in terms of aging as well as in all other areas of life. At the same, they suggest that this perfection is unreachable and that accepting imperfection may lead to a more wholesome aging experience.

Ultimately, the narratives discussed in the following act as a medium, providing meaning and insight into the discourses of age(ing) at the intersection of society, biology, and culture. According to Jan Baars this goes back to Aristotle who established the concept of ‘*mimesis praxeos*’ according to which “narrative is the imitation of action. Through stories, we communicate to others and clarify for them and to ourselves what the years meant, what it is to age, who we have become” (291). In the narratives I discuss throughout the next chapters, I thus seek to find the actions that make life meaningful, as well as the aspects that define age(ing) and the life-course.

## **II. Centenarians—The Stars of Aging**



The fascination with extraordinary longevity is ever-present in modern media. The *Guinness Book of World Records* names the oldest living person each year. This 'honor,' accomplished by centenarians as the longest living individuals only, is accompanied by numerous newspaper articles and sometimes even TV interviews. The *Guinness Book* itself, for instance, publishes articles such as "The World's Oldest People and Their Secrets to a Long Life" (Punt.). These articles usually contain basic information on the centenarians' life in a historical context as well as a section on diet and lifestyle, supposedly uncovering how they managed to live to extraordinary 'old' age. This fascination contradicts the much-criticized invisibility of 'old' age. Psychologist Tamara McClintock describes the phenomenon of invisibility in her own life: "I realized that when I walk down the street, younger people simply don't see me. Not a glance, not a smile, none of the customary, friendly gestures we're used to here in neighborly San Francisco. It was as if I actually disappeared from the sight of people much younger than I." Seeking out centenarians and reporting on them, contradicts this notion of invisibility, at least in public media discourse. Instead of showing for a generally new engagement with 'old' age, however, I argue that this visibility is rather connected to a form of sensationalism that accompanies extraordinary 'old' age.

This sensationalism is not tied to being the oldest living person on earth but to merely turning 100. This trend can be seen in many media outlets concerning a variety of topics. For instance, prior to the 2020 U.S. general election, there were a number of news segments on voting centenarians, including titles such as "101-Year-Old Anna Belfield Casts her Vote in Queens" or "104-Year-Old Ruth Rosner on Casting her Vote." These titles indicate that it does not matter whether a person is 101 or 104 years old. As long as they have reached a three-digit age, their act of political participation seems to be worthy of news coverage. Similar mechanisms can be seen at the morning show *Today!* which has an advertisement on their homepage reading "Today's Al Roker and our sponsor Smucker's are continuing Willard Scott's tradition of recognizing viewers turning age 100" ("Celebrate with Today"). Here, turning 100 seems to be an achievement worth being covered and celebrated. What is it, then, that makes this number so fascinating? For one, reaching a full decade is always considered somewhat of a milestone birthday; 100, as the first three-digit birthday seems to amplify this phenomenon. Further, once a person turns 100, they enter an elite group of those who lived longer than most other people, which, in turn, inspires visibility and fascination. Centenarians' institutionalized age thus exceeds the expected, leaving all other age categories without reference. If a new age group emerges, growing older than most other people, what are cultural expectations in terms of behavior, outward appearance, and physique? This shift in age categories makes age as a construct visible by denaturalizing it and, at the same time, encourages the fascination with this emerging age group.

The partnership between *Today!* and Smucker's not only points to a fascination that starts at a person's 100<sup>th</sup> birthday but also to a commodification of the centenarian lifestyle. Smucker's, primarily producing jam, peanut butter, and ice cream toppings, highlights the significance of extraordinary 'old' age for the food industry through the connection of their company to centenarians. Smucker's could thus be interested in advertising centenarians because it directly links their products to extraordinary longevity. In other words, in advertising centenarians, Smucker's suggests that consuming their products contributes to achieving a long and healthy life, using them to sell their product. The general fascination with centenarians becomes a marketing tool in this case. This marketing strategy is, however, only possible because, of a mechanism I call the centenarian paradox: even though being 'old' does not seem to be generally enticing in Western societies, becoming a centenarian appears to be a desirable goal to achieve. The longing for achieving centenarianism in turn creates a market for advice on food choices and healthy living which Smucker's seems to capitalize on.

One reason for the fascination with centenarians might stem from simple statistical facts. Christine Overall elaborates that "[a] small number of people attain the age of one hundred, and throughout the world nine times more women than men are aged one hundred or more. The probability the people in the West will live to one hundred has been doubling approximately every ten years" (9). Accordingly, as of now, living to the age of 100 is still rather rare, yet, the numbers of centenarians are constantly growing. Western societies are hence precisely at a point in time when the phenomenon is frequent enough to be noticed as such and, simultaneously, rare enough to still be regarded as something special.

The celebration of the number 100, as well as the statistical interest in people who have reached that institutionalized age, therefore suggest that this particular birthday marks a transition from being simply 'old' to becoming a 'paragon of aging' (cf. Robine and Vaupel) Looking at the narratives surrounding centenarians, I argue, offers insight into the processes that drive the fabrication of age categories and therefore into the mechanisms behind the cultural construction of 'old' age. The life narratives discussed in this section, however, do not only present the wider media discourse reporting *on* centenarians but—in some more than in others—the centenarians get to speak for themselves, offering a more nuanced approach to the aging process. In that connection James Holstein and Jaber Gubrium note that "[r]esearch has illustrated how time-framed identities such as 'teenager' or 'adult' are realized in and through the localized, symbolically defining actions of a wide spectrum of involved individuals, all of whom contribute to meanings of that life stage" (340). If turning 100, then, is the transition into the life phase of centenarianism, all texts dealing with this topic contribute to the cultural understanding of the category. As with teenagers or adults, the definition of this new category should be expected to differ from whatever category came before. Arguing that centenarians are, through

cultural interactions and texts, formed into a new age group suggests that there need to be characteristics that are significantly different from the preceding life stage of being merely 'old.' Ultimately, the life narratives discussed here show that there are mechanisms of fabricating centenarianism as a distinct life stage on the one hand, while centenarians themselves regard their own age(ing) as a continuum of 'old' age, on the other. I aim to discuss the means by which centenarians are fabricated through narratives originating from the people surrounding them, while they themselves tend to defy this fabrication. Ultimately, understanding the emphasis put on certain aspects of this life phase in order to make it distinguishable from its priors helps not only to understand how age categories are constructed but also to understand what aspects are inevitably connected to being just 'old.'

The texts I am concerned with are all accounts of centenarians who have taken more or less part in the creation of their own story. In order to provide a wide scope of different accounts of centenarianism, this section is subdivided into three chapters, each dealing with a subgenre of life narrative: a music video, featuring a centenarian's birthday party, a short documentary, capturing one day in the life of a centenarian, and a book-length (auto)biography. I am thus not only looking at the narratives themselves but also discuss how each text form can contribute to the overall discussions of what age(ing) means in a cultural, social, and biological sense.

The first chapter of this section deals with a centenarian as part of a viral internet phenomenon, the 2017 hip-hop video "Glorious" by rapper Macklemore (featuring Skyler Grey) in which he pays a surprise visit to his grandmother Helen for her 100<sup>th</sup> birthday. Despite this video being a form of life narrative only in a very broad sense, it shows desired behaviors connected to extraordinary 'old' people by staging an eventful day in a centenarian's life. As this video is a viral phenomenon with a younger target audience, it is not only influential in terms of images of 'old' age but also makes an extraordinary 'old' woman visible in a setting she would normally be excluded from. The video addresses issues such as age and visibility, as well as meaning, sexuality, and activity in later life.

The second chapter of this section deals with the short documentary "A Sunday at 105," following 105-year-old Aldéa Pellerin-Cormier for one day, inquiring about her life in extraordinary 'old' age, as well as her past and future. This film is a collaboration between Pellerin-Cormier and her great-grandson. In this intergenerational project, it is fruitful to discuss the questions deemed interesting by the 'young' great-grandson in combination to the answers and anecdotes of the extraordinarily 'old' great-grandmother. I am thus interested in what the points of inquiry of the great-grandson reveal about the image he, as representative of a younger generation, has about extraordinary 'old' age. Conversely, I discuss how the answers given by Pellerin-Cormier indicate a refusal to conform to the fabrication of her extraordinary age. This short documentary also addresses issues such

as gender, body, and temporalities in extraordinary 'old' age. Here, again, expectations of what it means to be extraordinarily 'old' and the behaviors that go along with it are challenged, yet, the documentary does this in a more subtle and less sensationalist way than Macklemore's music video.

After discussing two visual examples I will then continue my analysis of centenarians by looking at *Life is So Good*, the (auto)biography of George Dawson, an African American centenarian from Texas who rose to fame because he achieved literacy at the age of 98. This achievement questions the idea of cognitive disadvantages in 'old' age and suggests that it is indeed possible to learn new things at all life stages. As this is a narrative not only about being a centenarian but also about the entire life-course, it is particularly interesting to see how a life is narrated from this late life point of view. In other words, I am interested in the way the centenarian comments on his on past selves and the aging process as a whole, as well as how he is aged by the culture, he lives in. In connection to cultural and social structures, *Life is So Good!* highlights issues of the interconnectedness of age and race, as well as age and class. Finally, as a co-production of a centenarian, George Dawson, and his co-author, Richard Glaubman, the narrative offers an opportunity to discuss the ethics of life righting in terms of voice, agency, race, and extraordinary 'old' age.

## 2 “I feel glorious”: The 100<sup>th</sup> Birthday of Macklemore’s Grandmother

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In his 2017 music video to the song “Glorious” (featuring Skylar Grey) rapper Macklemore surprises his grandmother Helen on the day of her 100<sup>th</sup> birthday. A centenarian being part of a hip hop music video alone presents to be a juxtaposition of age categories as this musical genre is stereotypically assigned to be the taste of younger generations. This notion is emphasized by the activities shown in the video and the lyrics of the accompanying song. Through this juxtaposition and the way Helen is presented, it becomes clear that centenarians are seen as an age group that is certainly ‘old’ but a kind of ‘old’ that deserves rewards and recognition. Additionally, this video is to be seen as a part of the industry that uses centenarians as a sensation. Where Smucker’s tries to sell food products, Macklemore tries to sell his new song by shifting the focus on a phenomenon that does not seem too common and can thus draw the interest of a wider audience. Connected to this supposed aim of the video, it is important to note that this form of narrative is arguably only a life narrative in a very broad sense of the concept. Helen does not get to narrate her own life but performs a day that was not planned due to her own wishes but staged by her grandson. Yet, the way she acts around this staged setting as well as the way she is staged in the first place allow for a discussion of the constructedness of centenarians in particular and age(ing) in general.

It is especially because of the specific genre of a hip hop music video that the representation of Macklemore’s grandmother becomes important to an overall discussion of the construction of age(ing). Due to the fame Macklemore enjoys, this representation is bound to be seen by a wide international audience.<sup>1</sup> This becomes important in connection to Ulla Kriebner’s and Roberta Maierhofer’s argument that

[r]epresentations determine how we understand age and aging and influence the way we perceive others and define ourselves over the life course. Iconographies

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1 Here, the public interest in centenarians and Macklemore’s popularity may well have a mutual influence on the range of audiences reached by this piece.



and representations mark changes in social and cultural perceptions and have very real consequences in terms of social, political and cultural practice.” (9)

It is accordingly due to representations of age(ing) in the media that people are ‘aged by culture.’ Whereas that applies to any type of representation, it is those that reach a wide audience and maybe also an audience that has not previously been confronted with specific images of (extraordinary) ‘old’ age, in which the power of determination becomes stronger. While strongly contributing to the way extraordinary ‘old’ age is constructed within society, this new age testimony of centenarianism indicates how extraordinary ‘old’ age is perceived in Western societies.

In order to trace the implications this video makes for my overall discussion of extraordinary forms of age(ing), I will focus on three major aspects. First, I read the lyrics of the song “Glorious” with a focus on age(ing), arguing that the words contribute to the idea that turning 100 marks a new life stage. I then outline to what extent the lyrics contribute to the construction of this life stage. Second, I look at the actions taking place in the video, discussing how they foster an image of a sensationalized phenomenon and ask whether this video is merely another account of a positive aging narrative. In that light, I further elaborate on the ‘othering’ of centenarians, inquiring their relations to other age categories. Third, I shift the focus to the aging body. In dialogue with the discussion of positive aging I look at the way the focus on the centenarian’s body interacts with definitions of progress and decline, as well as with positive aging.

## 2.1 New Beginnings: Rereading “Glorious” in Terms of Aging Studies

At first glance, the lyrics of the song “Glorious” do not appear to have any connection to aging studies. They do not discuss matters of ‘old’ age or ageism but can be read as a general appeal for a positive change. The narrator describes their overcoming of hard times with the result of now feeling “glorious.” The idea of connecting the lyrics of the song to extraordinary ‘old’ age is then added by the artist through the music video accompanying the song. Because of the visuals of Macklemore’s centenarian grandmother, the lyrics of the song demand a rereading in terms of aging studies. The issue at hand is the way in which Macklemore, who claims on his own homepage that “[a]s artists, we are committed to using our platform, resources and creativity to have an impact on racial and social justice issues” (“Activism”), tries to use his voice in order to undermine prevalent and demeaning stereotypes of ‘old’ age. In this subchapter, I am thus especially interested in the contribution Macklemore’s lyrics make to the understanding of extraordinary ‘old’ age.

The song begins with the exclamation “[y]ou know I’m back like I never left” (Macklemore 00:38-00:41) which signifies a return. In the context of age(ing)

stereotypes and centenarianism, this return can be read as one from the realms of the 'waiting room' of the 'old,' as well as the invisibility connected to later life. Along the lines of this reading, turning 100 would mean that a person is given a second chance—that they can break out of the 'waiting room' and return to the world of the living once more. Turning 100 could then be seen as an 'antidote' to the ageisms people face in later life. By pointing out the number 100 as a threshold out of the 'waiting room,' the lyrics hint at a need to break out of something negative—'normal old age'—into something that is generally connotated in a more positive way—centenarianism. It appears the crossing of the threshold is possible for all those who turn 100 and are able to do "another sprint, another step, another day, another breath" (00:42-00:49), as Macklemore continues his song. Combined with the imagery of a centenarian, the lyrics of the song seem to have a message that go beyond the lines of a successful aging paradigm. On the one hand, Helen's breaking out of the 'waiting room' is only possible because she managed to age in a way that would be considered successful, on the other hand, in order to really be successful, she needed to cross the threshold of 100. This sets a higher bar of what is ultimately be considered positive or successful aging and implies that physical fitness alone may not be enough. Rather, an individual has to achieve an extraordinarily high institutionalized age—namely 100—to really be considered successful.

In addition to this notion of successful aging conveyed throughout the song, the lyrics suggest a plan to accomplish the stage of extraordinary 'old' age by stating "[w]anna piece of the pie, grab the keys of the ride" (00:56-00:59). This metaphor in itself can be translated into an analogy of the American Dream or a myth of U.S. American meritocracy: in order to get from 'rags to riches' a person has to work hard and take their destiny into their own hands by 'grabbing the keys of the ride.' This myth of the American Dream can then be connected to a neoliberal mindset, giving people the idea that whatever fortune they have to face in life is up to them. Accordingly, people who do not manage to 'grab the keys' have only themselves to blame for not getting 'a piece of the pie.' Connecting this thought to aging, would mean to read this quote as telling 'old' people that weather or not they are regarded in terms of decline or disengagement is due to their own actions. If they have lived their lives 'right,' that is, if they have worked hard and lived healthily, they will be able to abstain from the negative images of later life. The connection between life narrative, the life-course, and the American Dream has been previously made by Margaret Gullet who elaborates that "[w]hether a spur, or reward, the so-called American dream is a model national biography that shapes subjectivity and autobiography" ("From Life Storytelling" 104). Accordingly, every U.S. American life story should be, in one way or another, connectable to the concept of the American Dream. In Helen's case this connection means that it is now up to her, as a cente-

narian, to overcome the supposed decline forces of later life and to break free of the 'waiting room' of 'old' age.

These two quotes from the first stanza of the song paint the picture of centenarianism as a desirable phase in life that is achievable for every person who is willing to work hard enough to get there. Establishing this view on extraordinary 'old' age works through a clear cut, which is made between this desirable life stage and the one coming before. This becomes even more obvious when reading the refrain of the song: "I feel glorious, glorious/ Got a chance to start again/ I was born for this, born for this/ It's who I am, how could I forget?/ I made it through the darkest part of the night/ Now I see the sunrise/ Now I feel glorious, glorious" (01:33-02:00). The glorious feeling is only achieved after a new beginning. Only after rediscovering the joys of life, after going through 'the darkest night,' the narrator can enjoy the sunrise and feel good again. Enduring darkness in order to come to a new beginning can be read as a metaphor for having to endure ageism and isolation during 'old' age, before reaching the stage of extraordinary 'old' age. Only when turning 100, the dark period is overcome and the centenarian can now enjoy the rest of her life knowing that she has made it into the realm of the stars of aging. Read from the perspective of aging studies, the lyrics of the song distinguish between 'old' age and extraordinary 'old' age by implying the latter is an overcoming of the former. Interestingly, this differentiation of 'old' age can be seen as a continuation of the distinction between "independent and capable Third Age and a deep old Fourth Age that is characterized by sickness, frailty and dependency" (van Dyk, "The Othering of Old Age" 109). Centenarianism could then either be seen as a continuation of the third age or, as implied by the lyrics at hand, an overcoming of the fourth age.

Van Dyk argues that when it comes to age there are processes of othering at work "with the young-old being valued as other and the oldest old disdained at the other" (110). These mechanisms of othering work in comparison to midlife. By encouraging a comparison to other categories of 'old' age "Glorious" suggests that there is, indeed, a difference between them. At the same time, this comparison might work to disrupt the hegemony of the midlife by specifically *not* comparing centenarians to the middle-aged. The lyrics of the song then paint a glorified picture of centenarianism, especially by demeaning 'old' age in general. In that sense, the lyrics themselves, when connected to the subject of the music video, are of highly ageist nature. Further, it remains questionable whether the idealistic image of extraordinary 'old' age conveyed through the narrative of new beginnings is not an example of wishful thinking, deriving from a 'young' man who hopes there is a better future for his grandmother and ultimately himself.

Throughout the song, the tenor of the lyrics remains similar to the examples discussed above. The theme of a new beginning is a recurring one. Additionally, the lyrics specifically hint at the utopian imaginary of the life span beyond 100 to bring a second youth. In the second stanza it says "[w]e've been going in/ Since

we hopped out that DeLorean" (02:08-02:02:14.). Mentioning a DeLorean is a clear reference to the *Back to the Future* trilogy in which the protagonists use a converted DeLorean to travel through time. Hinting at this is one of the few direct references to time in the song. The lyrics here indicate some form of time travel which can have a twofold meaning. Either, turning 100 initiates a jump back to the supposed glories of youth and away from decline and disengagement or, the song ties in with the music video that shows a centenarian engaging in behaviors that are associated with a younger generation.<sup>2</sup> In that sense, the lyrics would describe a day of time travel for Macklemore and his grandmother. The take home message of both readings, however, is the same: there is a cut in a person's life once they turn 100. This cut allows them to go back to the time before the 'waiting room' and invite a new imaginary of a possible future free from decline.

Ultimately, reading Macklemore's lyrics through the lens of aging studies reveals that "Glorious" imagines extraordinary 'old' age as a new beginning after going through the phase of 'old' age. Thereby, it promotes the concept of active and positive aging in suggesting that extraordinary 'old' age is positive and can, like the American Dream, only be achieved if a person is willing to work hard for it. Thus, the lyrics of "Glorious" give an image of centenarians as an age group very much separated from other people who would be considered 'old.' By using his voice to give visibility to his grandmother, a centenarian, Macklemore's lyrics fail to include people of other age groups. Only through distinctively separating extraordinary 'old' age from what came before, the imagery of a possible future free from decline can be established. Now, the question presents itself, what happens when the video is brought into the context of aging studies, centenarians, and centenarianism, bearing in mind the implications of the lyrics.

## 2.2 "I wanna do it all": Extraordinary 'Old' Age and Extraordinary 'Young' Behavior

According to Haim Hazan, "the behavior of older people and their attitude towards themselves are shaped and reinforced by society's prevailing images of them. By adopting these images, the elderly in turn confirm and strengthen them" (33). Hence, as there are widely recognized cultural stereotypes of 'old' behavior, people are inclined to, at some point, adopt these behaviors which in turn confirms the stereotypes within a given society. Yet, Macklemore's grandmother, Helen, behaves in ways not conforming to widely recognized stereotypes of 'old' age. Consequently, her behavioral age does not align with an institutional 'old' age. Rather, she engages

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2 The theme of 'young' behavior and centenarianism which is prevalent throughout the music video will be discussed in detail in chapter 2.2.

in activities that directly challenge them and thereby question established cultural images. Simultaneously, showing a centenarian engaging in activities that would stereotypically be regarded more suitable for 'young' people, plays on the assumption that one can age positively and successfully, triggering the notion of Helen's narrative to be merely one of successful and positive aging. Yet, because the gap between expectation and behavior is extremely wide, the video raises the question if this sensationalized representation of centenarianism can at all be regarded as a positive one.

The surprise Helen receives in the music video is not only a visit from her grandson but, more importantly, a day of all sorts of birthday activities. In fact, after entering his grandmother's house, Macklemore tells her "we're gonna do whatever you wanna do" to which she replies "I wanna do it all" (00:26-00:32). Interestingly, this statement already goes against the expectations of 'old' age. Contrary to popular imaginaries, Helen does not conform to stereotypes of an elderly person living in the past but is eager to experience new things. In their article "Queering Aging Futures" Linn Sandberg and Barbara Marshall argue that it is a crucial part of successful aging to have a sense of a possibility of future: "In what follows, we expand our arguments to suggest that successful aging is not just about what one does in the here and now but contains an imperative for the future—an association of aging with possible futures" (3). This then goes along the line of Ricca Edmondson's analysis of meaning in life through a notion of 'development through time.' It becomes clear that concepts of successful aging and concepts of meaning are not always easily separable. In order to accomplish what would be considered successful or meaningful aging, it is thus crucial to be able or allowed to imagine a future. Even though the notion of future presented here is very short term, it is crucial that Helen still plans to do it all instead of uttering a stereotypically 'old' phrase such as 'I have done it all.' This, then, goes along the lines of the lyrics of the song, indicating that Helen has emerged from the period of futureless aging by turning 100. Helen's 'doing it all' includes going to the mall, buying a pair of sneakers, singing Karaoke, playing video games, throwing eggs at houses, and enjoying the performance of a stripper at her birthday party. All these activities contribute to the imagery of age(ing) provided in this video. Other than the lyrics' rather unspecific notion of new beginnings, the activities Helen engages in suggest what these new beginnings can look like and, at the same time, indicate what 'normal old age' does not look like. At the same time, these new beginnings remind the audience of 'young' behavior, indicating that the desired form of aging from a 'young' perspective, would indeed be a continuation of what they know for the most part.

Showing a centenarian going on a shopping trip indicates that centenarians are an active part of modern consumer culture. Helen is able to go to the mall and actively select a pair of sneakers while enjoying herself and spending money. Her choice of shoes further indicates a connection between institutionalized age and

assumptions made about a person's behavior or personal taste. Macklemore suggests a particular type of beige shoe with velcro fastener that would be associated with older women (01:05). Thus, a certain type of consumerism is expected from certain age groups (and genders). In that connection, Stephen Katz argues that exactly these associations are being eradicated more and more as marketers try to sell an ageless self. Accordingly, especially an ever-growing spending power amongst senior citizens

has inspired real estate, financial, cosmetic, and leisure enterprises to target a growing and so-called 'ageless' seniors market (usually pegged at 55+) and to fashion a range of positive 'uni-age' bodily styles and identities that recast later life as an active, youthful, commercial experience. (*Cultural Aging* 190)

In other words, those who can still join into a consumer culture that is not specifically associated with a certain age or, at least not with being 'old,' are specifically targeted by various industries with ageless products. In turn, the availability of these items sparks a new need for them; if a majority of people over that age of 55 try to appear ageless, it becomes an imperative for the individual to join this movement in order to remain an active member of society by interfering with one's outward age. It is, for instance, less socially accepted to wear naturally greying hair than to dye it another color. Hence, products that change visible indicators of an advanced age such as hair dye and anti-aging creams are as important as clothing and other items that are considered to be ageless. According to the advertised need of agelessness, Helen turns down her grandson's suggestion and indeed refuses to align to the consumerism that is expected from someone categorized as 'old.' Interestingly, however, the sneakers Helen finally buys in the video are not ageless but, in their style, rather connotated with youth culture, as she goes for trendy white sneakers (01:16). She thus goes beyond the concept of agelessness, actively protesting the cultural imaginaries of 'old' age as well as the connected social expectations.

Instead of confirming to the general movement towards ageless attire, the video plays with expectations of 'young' and 'old' through the use of everyday items. The shoes here serve as a material manifestation of age appropriate or inappropriate behavior. Buying the beige, old-fashioned shoes, would have been the expected consumer choice, buying the white, trendy sneakers at first glance seems to break with stereotypes of 'old' age. Yet, the question remains whether this purchase is only acceptable because it is significantly different from any expectations. Because the video goes against the expected, it remains interesting for a younger audience. The juxtaposition of institutionalized age and behavior is thus a tool to produce extraordinary 'old' age as a phenomenon.

The material manifestation of age inappropriate behavior in the form of shoes is supported by the activities Macklemore and Helen engage in during the video,

most of which are activities considered to be suited for a younger population, or plain childish. Helen's behavioral age is thus framed as being much younger than other age categories would imply. Yet, the act of singing karaoke, for instance, plays with images of 'old' age and (in)visibility. Kathleen Woodward argues that "[i]n our mass-mediated society, age and gender structure each other in a complex set of reverberating feedback loops, conspiring to render the older female body paradoxically both hypervisible and invisible" ("Performing Age" 163). While, as mentioned above, everyday encounters tend to make aged individuals feel invisible, media representations, according to Woodward, are complex interplay of hypervisibility and invisibility. Invisibility, for there is a lack of representation, hypervisibility for the aged female body appears as strange and denaturalized moving it into direct focus of the onlooker. This concept is especially applicable to the aged female body, which appears to be consistent with the way Helen is portrayed. Accordingly, the extraordinary 'old' woman is made hypervisible in the sense that she is forced into the spectators' perception by being put into a situation that does not look 'natural' for her age. This goes along the lines of Charyl Laz's discussion of the naturalization of age(ing) in general: because Helen behaves in a way that counters stereotypical expectations concerning her age, not only she, as an aged individual, but age itself becomes visible. By breaking with these stereotypes, the video encourages its audience to think about whether age should be a determining factor of a person's actions or if age really is just a number.

Further, Helen's performance can be read as a message to younger generations, telling them that growing 'old' is not something to be dreaded but that they can escape the 'waiting room' of 'old' age through their personal attitude. It is crucial to note, however, that Helen's behavior is depicted as being fabricated by her grandson—a famous representative of the younger generations—as he puts her into the spotlight, presenting her in ways that counter normative assumptions of what being 'old' should look like. In that connection Sharon-Dale Stone points out that

[i]n contemporary Western societies, it becomes difficult to really see images of old people engages in activities usually associated with youthfulness. . . . When such evidence exists, dominant ideology encourages the dismissal of these people either as too unusual to be taken as exemplars of old age, or as not really old. (61)

In other words, if 'old' people engage in 'young' activities, they are either considered too much of a curiosity to be considered in discourses about 'old' age or they are regarded as not being 'old' in the first place. Consequently, buying sneakers for a centenarian or letting her perform in a karaoke bar raises the question of how she is positioned on the spectrum of age. Does Helen become a curiosity or is she regarded as not 'old'? Reconnecting this argument to the discussion of the song's lyrics implies that Helen is regarded as not merely 'old' but, since she is a centenarian, as someone who has overcome being 'old.' Instead of being portrayed as

'not really old' or ageless, Helen appears to be staged as beyond aging. In other words, this video suggests that centenarians as the stars of aging are placed outside any existing age categories, as they have 'won' the aging process. Nonetheless, the emphasis on centenarianism is needed for this new age category to function. Consequently, at least in terms of institutionalized age, Helen is not depicted as ageless at all. Rather, the focus on institutionalized age allows for the other age categories go beyond any expectations of age-related behaviors.

This line of thought is again reinforced by van Dyk's discussion of the 'othering' of 'old' age as a universal phenomenon. In that connection she argues that third agers—who she closer defines as "fit and healthy retirees in their 60s, 70s or even 80s" ("The Othering of Old Age" 109)—are romanticized in Western societies to a degree that is comparable to colonial concepts of 'the Oriental' as exotic (cf. Edward Said, *Orientalism*). Van Dyk elaborates that

[a]s with the 'exotic oriental', the widespread praise for elderly people who are capable, warm and charitable seems harmless at first sight . . . The fact that this generalizes sympathetic praise serves precisely to reinforce the assumed superiority of the imagined 'agelessness' of midlife becomes visible only throughout the lens of postcolonial studies. ("The Othering of Old Age" 114)

Accordingly, the seemingly encouraging discourses of positive or active aging are, comparable to concepts of the noble savage or the exotic oriental, derogatory toward the aging population with regard to their reinforcement of a powerful midlife norm. An 'old' person, in other words, can only be a valuable member of society if they are regarded as active or positive from a midlife perspective. Connecting this framework to Macklemore's rap video, two things become instantly clear: The process of othering is not only tied to the lyrics of the song but also to the imagery provided within the video. Helen's preference in sneakers as well as her various performances throughout the video would not be noteworthy if she was not considered to be some sort of 'other.' By showing her having fun with her grandson, her life stage is indeed romanticized. However, it is crucial to note that this romanization stems from the way she is staged by Macklemore. As the romanization of indigenous peoples in terms of concepts such as the 'noble savage' happens from a Eurocentric point of view, the romanization of the centenarian happens from a midlife perspective. Consequently, the video portrays a well-functioning centenarian in surroundings that would be considered fun from the midlife or 'young' adult perspective. In other words, Helen is acting according to an imaginary of 'young' people who wish later life to be a continuation of their current state. The major 'positive' element of Helen's performance is then the fact that she indulges in especially these behaviors that seem desirable to the 'young' audience of the video. However, even though her actions seem like a continuation of 'young' behavior, she is still considered to be different, for instance, to all the other people in the karaoke



bar. Her appearance there remains a phenomenon. At the same time, the lyrics of the song suggest a new life stage. In addition to the staged uniqueness of a person like Helen, this reinforces that centenarians are not only an 'other' from the midlife perspective but also an 'other' within 'old' age itself.

Thus, even though Helen is subject to a positive 'othering' process, she is neither part of the category of the third or fourth age nor of the midlife, as her institutionalized age has long exceeded the parameters thereof which is emphasized throughout the video not only because the narrative evolves around Macklemore surprising his grandmother for her 100<sup>th</sup> birthday but also because her actual birthday party is depicted in the video. This party is celebrated with a cake, including a candle with the number 100. Even without having read the description provided in the beginning of the video, it is clearly indicated that this is a surprise for Helen's 100<sup>th</sup> birthday. Interestingly, although this is Helen's 100<sup>th</sup> birthday, in the instance where she blows out the candles on the cake (02:57), it is her grandson who is presented in the center of the group of five, indicating that, even though Helen might have stepped out of the 'waiting room' through her extraordinary age, he, as a representative of a younger generation is the most important person in this situation. Consequently, as already indicated in the lyrics of the song, the video portrays centenarians as separate from other age groups. Instead of being a continuation of midlife, becoming a centenarian is presented as a new phase in life that allows going back to some youthful behaviors and thus a braking free from the 'waiting room' of the 'old.' However, this breaking free does not mean that a person is not considered as an inferior 'other' anymore.

Especially with the connection to postcolonial studies, it becomes clear that this romanticizing of centenarians points to the superiority of midlife. Van Dyk elaborates that

[o]ne of the major achievements of postcolonial scholars is their deconstruction of positively connoted stereotypes of the 'authentic other'. Said and others have demonstrated that the structural devaluation of the Oriental goes hand in hand with a striking enthusiasm for and romantic idealization of the same, ending up in a veritable 'Indomania.' ("The Othering of Old Age" 113)

Postcolonial criticism has thus long exposed that seemingly positive concepts such as the 'noble savage' or the 'exotic oriental' in fact strengthen the power structures of colonial societies by emphasizing the weaknesses of the 'other.' The same goes for elderly people in general and, in this case, Helen in particular. Not only does her grandson remain the drive behind all activities they engage in, he is also the motor in staging her in a most efficient way for his own success. Much like exploiting indigenous cultures for the entertainment of the white settlers, this video could then be read as an exploitation of centenarianness for the purpose of the success of the middle ages. In that sense, the juxtaposition of institutionalized and behavioral age

in this video could be read as a tool to increase the romanticizing of centenarians in order to make them an even more valuable commodity.

Ultimately, the behavior depicted in this video has a manifold influence on the construction of extraordinary 'old' age. On the one hand, centenarianness is depicted as a desirable state in life, which has the power of reversing structures of 'old' age. By portraying the 100<sup>th</sup> birthday as a gateway to a new life stage, the video, especially in connection with the lyrics of the song, depicts centenarianism as a life stage that is inherently different from what came before. Only as a centenarian, then, Helen is granted to 'do it all' once again. On the other hand, drawing from the connection of aging studies and postcolonial studies reveals that this extreme form of 'othering,' achieved through the establishment of a hypervisibility, serves as a means to construct the life phase of centenarianism as the inferior other or even as a commodity for the entertainment of younger generations. While Helen is thus still part of consumer culture as a buyer, she is also sold, revealing the actual weakness inherent to being extraordinarily 'old.'

### 2.3 Centenarianism and the Aging Body in the Realms of a Hip-Hop Video

In the previous subchapters, Helen's aging body and therefore the concept of physical and outward age has only been addressed marginally. However, discussing the construct of age requires a thorough analysis of the body and its representations. For the purposes of this subchapter, the focus will lay on three major points: first, how is the aging body presented with regard to (dis)ability? Second, how are the outward features of the body incorporated into the construct of age? And third, how is the body put into the context of the video and how is it used as a meaning bearing instance?

Popular images of the aging body are inextricably linked to concepts of decline. Besides fears of a declining mind in form of dementia, assumptions about the aging process work upon a fear of a growing dependence due to a lack of physical abilities. In that connection, Anita Wohlmann elaborates that

[t]he decline narrative that is imagined as a universal trajectory of the aging process . . . represents a prejudiced (or ageist) cultural concept of what it means to age because it suggests that growing into old age inevitably entails loss of health, vitality, social power, beauty, or sexuality. Such a cultural imaginary about age and aging can result in young people's feelings of repulsion and fear when they think about growing older. (26)

The main points Wohlmann connects with the decline imaginary refer to the aging body; the physically 'old' body is believed to be not healthy, beautiful, or (sexually)

active. This image not only fosters discrimination against the 'old' but also fear of growing 'old' in younger generations. Here, the representation of the extraordinary 'old' body in a hip hop video becomes particularly important because it can influence this very fear of decline in its primarily youthful audience. It is hence especially crucial to look at the representation of the extraordinary 'old' body, as well as outward appearance in Macklemore's music video.

As with every human encounter, the first thing standing out about Helen's body is her outward appearance which bears clear features of 'old' age that, contrary to many popular depictions, are not hidden. Helen has grey hair and a substantial number of wrinkles, countering a notion of her depiction as ageless. At the same time, she paints her fingernails and wears stylish jewelry and sunglasses, attributes not necessarily connected to 'old' age. When it comes to outward appearance and 'old' age, Sharon-Dale Stone argues that

[i]t's not at all difficult to find images of people who actually look old. We can look, for example, to august individuals such as Mother Teresa who died in 1997 at age 87, Desmond Tutu who announced his intention to retire in 2011 at age 79, of Queen Elizabeth of England who at age 85 keeps up a busy schedule of public appearances. Each of these people is famous for reasons unrelated to age, physical appearance, or ability to entertain, and so now that they are old, no one needs to hide evidence of their aged bodies." (59)

If only people who are *not* primarily known for things that related to age or outward appearance are allowed to actually appear 'old,' what does that indicate for the appearance of people who are *only* known because of their age? Helen is only part of this music video because of her extraordinary 'old' age. In that sense, she has to look 'old' to some extent in order for her outward age to match the audience's expectations and signify extraordinary 'old' age at all times. The grey hair and the wrinkles are thus a necessity for her appearance, yet, it is interesting to see how her outward age is complemented by the 'young' accessories of fashionable sunglasses and painted nails. Consequently, Helen gets to do both, look 'old' and remain 'young.' In terms of representation, this indicates again that centenarians seem to have a special place on the aging spectrum. One could argue that once a person turns 100, they do not have to stick to normative structures anymore. As opposed to other 'old' people, they are allowed to publicly display their wrinkles without being sanctioned for looking 'old' or frail. Yet, the representation makes clear that Helen is a 'hip' person, juxtaposing her 'old' features against the way she dresses. Ultimately, this juxtaposition informs a representation of extraordinary 'old' age that defies notions of decline, as it shows that wrinkles alone do not mean the end of life as we know it. Instead of trying to negate outward age, it becomes clear that this representation merely speaks to a redefinition of the negative connotations that go along with aged features. Helen's representation hence implicitly

suggests that underneath the threshold of the institutionalized age of 100, a person needs to try to appear 'young' in order to be visible in society whereas above it, this is not the case. Here, proudly wearing signs of 'old' age adds to Helen's charm.

Similar mechanisms apply to Helen's able-bodiedness. While she apparently lives independently, she uses a walker to move around, which counters images of hyperability often connected with positive aging. This hyperability is established by portraying 'old' people in public discourses who emphasize their ability to be physically active or to merely act as independent individuals.<sup>3</sup> These representations focusing on ability and independence implicitly underline the decline narrative, as they portray life as only worth living as long as it is an able-bodied life. Conversely, the walker, Helen is presented with, becomes another accessory, something that is just there, naturally belonging. In this instance, Helen's overall performance is the focus and the question of able-bodiedness moves to the margins. If the walker is not given any more significance than the sunglasses Helen is wearing, for instance, what does that indicate for centenarians and the decline narrative? If the decline narrative is an imperative story of aging, neglecting the walker as a focal point can be read as countering this imaginary. At the same time, showing a person dependent on a walker might redeem the video in terms of promotion positive aging. Marvin Formosa elaborates on the latter concept by saying "the positive aging discourse portrays older people as able to counteract the effects of aging through personal effort" (29). Connecting this statement with the above-mentioned assumption that 'old' age is primarily visible through the body, a person only ages positively as long as no physical aids are necessary. Consequently, showing Helen in need of physical aid works against the positive aging narrative conveyed through the lyrics of the song. As well as her 'old' outward age, the centenarian's compromised ability is okay to appear in the video because she has passed the milestone of turning 100. The video refuses to tie into a biology centered imaginary of age(ing) without ignoring the significance of the aging body. At the same time, treating the walker as mere accessory, the video suggests that needing physical aids does not compromise the worth of a life in any way, thus countering imaginaries of disability as failure.

Connected to the narrative told through the lyrics of the song, where it seems that becoming a centenarian is like a phoenix rising from the ashes, the centenarian body is allowed to appear 'old,' opposing demands to hide signs of 'old' age. Nonetheless, by displaying the walker as a mere tool, complementing Helen's persona, there is no imaginary of decline connected to it. Having reached the institu-

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3 One individual exemplifying the concept of hyperability is, as of July 2021, 86-year-old Earnestine Shepherd. Shepherd was named the "world's oldest bodybuilder" by *The Guinness Book of World Records* in 2010 ("Meet Earnestine"). The focus on Shepherd's fitness leads to an imaginary of her as not 'old' precisely because she is hyper-able.

tionalized age of 100 appears to be enough to liberate the centenarian body from these associations. In that sense, and building on her previously discussed behavior within the video, Helen does not seem to be fragile although her body shows obvious signs of 'old' age. According to Macklemore's representation of a centenarian, this newly emerging age group then exists outside the rulebook of normative aging, meaning that the concepts developed to describe aging phenomena do not seem to be entirely applicable to the imaginary of a centenarian age group. This becomes even more apparent by looking at the way Helen's body is presented in connection to younger bodies and how it is then positioned within the hip-hop video which I will do in the following paragraphs.

Besides the obvious relation of the aging body to the question of ability, there are other scenes in Macklemore's music video, directing the gaze towards body related issues. For instance, he takes his grandmother to a tattoo parlor where he gets a tattoo with her name while she watches (02:11-02:20). Here, the significance lies precisely in the fact that Helen does not get a tattoo herself but merely acts as a bystander. Modifying the body with everlasting ink seems to be the invisible line that the centenarian will not cross. Her body can be put into the setting of the tattoo parlor, but it cannot be engrained with a tattoo itself. Moreover, getting a tattoo for the sake of advertising her grandson's music may exceed the personal sacrifice any person would be willing to make. Referring to a movement of people using piercings and tattoos to satisfy apparently pre-modern desires to modify bodies, Christian Klesse states that "[t]he intense individual act of getting tattooed or pierced, however, for Modern Primitives has also the meaning of *creating collectivity*" (310). Modern Primitives are, in the discourse used by Klesse, those individuals who change their bodies permanently through the above-mentioned means. Whereas the terminology used here is certainly controversial, the relationship of body modification to individualism as well as collectivity is crucial for my argument. Considering that this music video shows the 'young' body getting to do it while the 'old' body remains inkless establishes this scene as a denial of both individuality and collectivity for the extraordinarily 'old' body. Apparently, further individualizing her body with a tattoo would overstretch the new possibilities the centenarian now has. She is neither allowed to enter the collective of the tattooed nor to individualize her body with this permanent change. This point is crucial in order to see that becoming a centenarian is not simply going back to the ways of midlife but is still connected to many restrictions of 'old' age, especially when it comes to the body. Referring back to van Dyk, this again stresses that centenarians are the 'other,' compared to the midlife, yet, a more desirable 'other' than 'old' people under the age of 100. In terms of the othering process, centenarians thus present a third form of 'other' in terms of 'old' age, which I will call an other 'other.' Furthermore, it shows how, even though Helen, as a centenarian might have overcome issues of invisibility, there are restrictions to her individuality. Showing

her getting a tattoo would overstep normative assumptions of body art being restricted to the non-wrinkled skin. Consequently, this normative assumption works as a restrictive entity, denying the extraordinary 'old' person access to a collective of 'young' people who admire the aesthetics of tattooed skin. Using aesthetics as a means of contrasting institutionalized 'old' age is thus acceptable as long as it is not permanent. Wearing the 'youthful sneakers' might only be acceptable because Helen is able to take them off at any time and change into something that would be considered more age appropriate.

Connected to the non-permanence of Helen's actions, is a sense of performance. As previously mentioned, Helen is staged as a model centenarian by her grandson. Accordingly, there is a certain performativity within Helen's actions. In her discussion of the perception of transgender bodies in society, Judith Butler argues that "the sight of a transvestite onstage can compel pleasure and applause while the sight of the same transvestite on the seat next to us on the bus can compel fear, rage, even violence" (907). While, of course, gender and age are not congruent in their construction and the discrimination towards the trans\* community is in no way comparable to the mechanisms of ageism, it is fruitful to borrow Butler's argument on performativity. As long as the audience knows that what they get to see is a performance of something they would consider to be outside of the norm, they are inclined to accept a variety of bodies for the sake of entertainment. In the 'real' world, however, the existence of these bodies is much less approved of. For the reading of centenarianness in "Glorious," this means that Helen's being staged as other 'other' may only work so well because the audience is very aware that this is a mere piece of performance. In other words, if Helen was to really sing karaoke, people may not be as approving. This then presumably would not lead to violence but to the very exclusion from society that is expected in 'old' age. Restricting her to change her body permanently, even for performance's sake—getting a tattoo could be performed, after all—shows that even within this staged environment, constraints of 'old' age still apply. While this sense of performativity certainly stretches the possibilities of representation in Macklemore's music video, I will argue throughout the next chapters of this book that a sense of the centenarian as other 'other' is still prevalent, even if the element of performance is reduced. That is, to some extent all centenarian narratives discussed here go beyond stereotypes of 'old' age. Yet, this notion is more subtle when the element of performance is scaled down in favor of a sense of normality.

When it comes to the aesthetics of her body, Helen is depicted in a way that meets normative concepts of femininity. She sticks to the conventions of doing her hair, however grey it may be, and painting her nails, which are beauty enhancements expected from females in Western societies. Sandra Lee Bartky transfers the Foucauldian model of the Panopticon to the female body, arguing that social mechanisms of self-regulation occur with regard to the female body in terms of

dictating rules of make-up, clothing, and sizing, among others. In that connection, she argues that “[t]o succeed in the provision of a beautiful or sexy body gains woman attention and some admiration but little real respect and rarely any social power” (24). The problem with female aging is related back to the body, as the aged body is not considered as beautiful and sexy anymore. In the video, however, Helen attempts to stick to the norms expected of a woman in terms of outward appearance. She wears fashionable sunglasses, paints her nails, and generally seems to take care of her outward appearance. Importantly, she achieves this through non-permanent accessories, only. She does specifically not dye her hair or use Botox. In that sense, her outward appearance in itself becomes a juxtaposition of the physical outward signs of ‘old’ age, which seem to be acceptable, and the ‘young’ accessories used to complement this appearance.

Nevertheless, she is not portrayed as beautiful or sexy, rather, as someone who could have been beautiful and desirable a while ago. Although sexuality appears within the video, it is outsourced and portrayed in a way that does not directly apply to Helen. Instead of allowing the centenarian to be sexy and desirable, a stripper turns up at her birthday party (03:11-03:35). This suggests that Helen is still interested in sexual encounters, yet, she herself is not the sexy component in the equation. This portrayal of sexuality shows the social mindset towards elderly people and their bodies: Sexual activity in ‘old’ age is generally denied because ‘old’ bodies are deemed unattractive in a way that provokes displeasure in many people when thinking about them in intimate contexts (Gewirtz-Meydan and Ayalon 648). Ultimately, it is Macklemore who stops the stripper from undressing completely and thereby revokes the normative assumption that sexuality becomes a taboo in later life. Here, the addressee of the video becomes an important factor: As this day is staged for Macklemore’s fans, and therefore a presumably younger audience, sexuality needs to be reined in, making the encounter with the stripper rather a cute than a sexy one. It seems to be funny to see older woman struck with abashment while watching a ‘young’ man undress while impossible to see them actually engage in the ritual.

The stripper scene does not only speak to the portrayal of ‘old’ age and sexuality but also adds to the juxtaposition of age categories. On the one hand, inviting a stripper to a party seems to be more common in early adulthood; for instance, at bachelorette parties or coming-of-age birthday parties. In these settings, the stripper seems to serve as a rite of passage into adulthood or married life. Putting a stripper into the setting of a 100<sup>th</sup> birthday party, can then be read as also signifying a rite of passage from ‘old’ to extraordinary ‘old.’ The extraordinarily ‘old’ body is allowed to be interested in sexiness, whereas in former years the topic of sexuality was completely erased from public discourse. On the other hand, juxtaposing the ‘young’ body of the stripper and the extraordinarily ‘old’ body of the centenarian leads to a confirmation of the social mechanisms operating in terms of age and

sexuality. The 'young' male stripper can perform for the centenarian female as long as it is absolutely clear that this scenario will never be more than a performance. The fact that Macklemore is eager to break up the scene thus speaks to the taboo of sexual activity among the elderly and confirms that even though centenarians break free of some assumptions of 'old' age, they are still expected to stick to others.

All in all, looking at the extraordinary 'old' body in Macklemore's music video provides a variety of different angles, that ultimately suggest that centenarians may live partially outside the narratives of positive aging and decline and are yet bound to confirm other stereotypes of 'old' age. However, the grappling of decline and positive aging are crucial findings. Although the analysis could, by itself, not uncover the mechanisms behind these renegotiations, the next chapters will serve to trace these concepts through other narratives of extraordinary 'old' age in order to shed light on how and if these concepts are redefined in the stories of other centenarians.

## 2.4 "Glorious" and the Portrayal of Extraordinary 'Old' Age

In the music video for the song "Glorious," age(ing) is addressed from a social, a cultural, and a biological angle. Being a cultural artefact itself, the video speaks to a cultural imaginary about centenarians that it may in turn well influence. It speaks to social norms and expectations that are often based on these cultural imaginaries and suggests that for centenarians, these norms only partly apply. Finally, it negotiates the biology of aging by presenting the aged body without giving it the defining power over Helen's age. It thus remains a question throughout the following chapters whether this approach to the interconnection of culture, society, and biology may lead to a more nuanced understanding of age(ing) in general.

Nonetheless, the aging body proves to be a crucial element when it comes to discussing the aging process in general. While Helen's behavioral age is portrayed as much younger than her institutionalized age and her outward appearance can be supplemented by 'young' accessories, her body seems to be caught within the expectations of 'old' age in the sense that it is presented as undesirable and unchangeable. However, being able to engage in all these activities at the age of 100 may itself be regarded as a juxtaposition of physical and institutionalized age. Yet, when it comes to the body, the stereotyping concerning 'old' age seems to be so deeply engrained in cultural imaginaries that even the centenarian cannot overcome them completely.

The discussion of the video has made clear that centenarians do not only hold a special position within society as they are seen as aging role models, but also that their extraordinary 'old' age sets them apart from other aged people in terms of the way their age category is socially and culturally constructed. Instead of showing



Helen as “conservative, inflexible, and resistant to change . . . incapable of creativity, of making progress, of starting afresh” (Haim 28), a representation that would be stereotypical for ‘old’ age, Macklemore presents his grandmother as a modern woman who is capable of having fun and look toward the future. Besides painting a rather glorified picture of centenarians, however, the video reinforces ageist structures through the clear distinction between centenarians and non-centenarians. By establishing turning 100 as a new beginning, the video and the song suggest that ‘old’ age before reaching this milestone is undesirable and negative. This reinforces the decline narrative of ‘old’ age even though being a centenarian appears to be more or less free of these derogatory concepts. At the same time, the video emphasizes that, even though becoming a centenarian is more desirable than being merely ‘old,’ extraordinary ‘old’ age does not present a continuation of midlife. Rather, according to the music video, centenarians are a distinct age group that needs to be admired. The video then explains the centenarian paradox by emphasizing the difference between ‘old’ and extraordinary ‘old.’

While contributing to the cultural construction of age categories, the video, unlike many other accounts of centenarians, leaves out how Helen got to live this long. The audience is merely presented with the fact that she has recently turned 100, there are no accounts of her diet, exercise schedule or general lifestyle. This could be connected to the intended audience of the video. The generally younger audience of a hip hop video might see themselves as too far away from ‘old’ age to even think about how to live to 100. The distinct genre of the hip hop video also shows only how the ‘young’ rapper stages his grandmother in order to serve his commercial interests best. In that sense, Helen is the centenarian icon that people *want* to imagine and ultimately want to become.

For the considerations within the next chapters, it is important to note that Helen represents a very normative centenarian. She is female, white, and well situated; all three factors add to a person’s life expectancy. As she represents a norm within her age group, it will be interesting to see to what extent the image of centenarianness differs among people who deviate from that norm. Moreover, Helen is depicted on a special occasion—her birthday. Hence, her behavior is not necessarily a depiction of an everyday behavior. Nonetheless, the video shows that the lifestyle presented is possible for centenarians to engage in. As opposed to this, the next chapters will deal with narratives that chose a more every-day approach to the topic of centenarianism. Further, I will use the next chapters to elaborate on the way centenarians are depicted in other forms of life-narratives and how these depictions add to or contradict Macklemore’s presentation of his grandmother and what different aspects of extraordinary ‘old’ age they address. Since the voice of the centenarian herself has been absent from this chapter, the following chapters will pay special attention to the break in perspectives on aging between the middle-aged producers of the narratives and their centenarian subjects.

### 3 The Normality of Being a Centenarian: A Day in the Life of Aldéa Pellerin-Cormier

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After having discussed a very popular example of a centenarian in the previous chapter, this section presents a shift in genre. While I still focus on the construction of extraordinary 'old' age in centenarian narratives, the subject of this chapter is the short documentary, "A Sunday at 105," which is significantly less popular than Macklemore's music video "Glorious." Comparing the views both videos got on *YouTube* suggests that the music video for the song "Glorious" has been watched over 200,000 times more often than "A Sunday at 105" (as of July 2021 247,030,038 as opposed to 2,880 clicks). These numbers are of course not entirely reliable since both videos are available through numerous sources in which the overall ratio might differ. Nonetheless, the numbers indicate a trend for a significantly wider reach for Macklemore's music video. Furthermore, while the music video addresses a demographic of rap music fans, the documentary discussed in this chapter is designed for people who are either interested in documentary film, living in Quebec, Canada, or, very specifically, aging lifestyles and the representation of extraordinary 'old' age. While Helen from "Glorious" is thus presented in a way that designed to sell to a younger audience and that highlighting a special day with special activities, Aldéa Pellerin-Cormier in "A Sunday at 105" is portrayed in an every-day scenario, drowning out the noise of sensationalism.

"A Sunday at 105" is described on the Homepage of the National Film Board of Canada as follows:

A 105-year-old Acadian agrees to be filmed one Sunday as she goes about her daily routine and ruminates on life. Filmed by her great-grandson, Aldéa Pellerin-Cormier comments wisely on politics, sex and religion. From getting ready in the morning to drinking her nightcap before bed, every moment is punctuated with a witticism or existential thought. Respectful of the old woman's privacy, Daniel Léger's first documentary looks at wisdom, serenity and enjoyment of life. ("A Sunday at 105: Synopsis")

This short introductory text not only provides information about the documentary's protagonist, it also already contributes to the way the centenarian is pre-

sented to the audience. For instance, the reader learns that the documentary's director is also the centenarian's great-grandson. There is a familial relationship between the maker of the narrative and its subject. As well as in the previous chapter "A Sunday at 105" thus not only deals with a centenarian but with the relationship of a centenarian to her (great-)grandson and is therefore a representation of a relationship between 'old' and 'young.' Furthermore, the text provides the same ever-present terminologies, so commonly used within the discourse surrounding centenarians. The centenarian appears to be wise, has many existential thoughts, and is presented as a 'historic' person, as she is not introduced as Canadian or Quebecoise but rather as Acadian, which stresses her heritage as descendent of French settlers.

The moviemakers, on the other hand, are established as 'respectful of the old woman's privacy' which serves as a disclaimer to anyone who might accuse this documentary of using the centenarian for their own profits. This disclaimer becomes even more interesting when looking at the modes of production of the video. The thirteen-minute clip was filmed by Daniel Léger as part of the Tremplin Program of the National Film Board of Canada. This "Canada-wide competition is for emerging filmmakers from Canada's French-speaking minorities looking to make their first or second documentary" ("Tremplin Program"). This documentary about a centenarian is thus used by its director to further his own career as a filmmaker. The centenarian, again, becomes a commodity and the object of another person's artistic fulfillment.

As well as in Macklemore's music video, in "A Sunday at 105" the centenarian is used to attract attention. However, the short documentary provides a much more 'ordinary' image of a centenarian by not showing her in settings which would typically be associated with 'young' age. Rather, "A Sunday at 105" invites viewers into the living room of a person that would, with the sole exception of being over 100 years old, be considered utterly normal. She spends her time, cleaning her house, engaging in physical activities, praying, or visiting with her family. In that connection, one could claim that in "A Sunday at 105" the sense of performativity so prevalent in "Glorious" is significantly weaker. This might be one reason why, as previously mentioned, the attention generated by the respective videos is significantly more prominent in Macklemore's case.

I am hence interested how this very different format of documentary film works to construct what it is like to be a centenarian. Here, it is particularly important to focus on the way being a centenarian is portrayed as something extraordinary within an ordinary life. In that sense, this documentary is not as much about juxtaposing 'old' institutionalized age with 'young' behavior, but more about pointing toward the fact that being a centenarian itself can present a juxtaposition to an expected life-course. In that sense, the institutionalized age of 100 and over is so unbelievable that it juxtaposes all other categories of age in itself: As centenarians

are simply too 'old' to exist, of course their institutionalized age does not match their outward, behavioral, or physical age. By simply turning 100, they defy stereotypes of 'old' age, as they outlive them. I argue throughout this chapter that the archetype of the centenarian as the star of aging is not deconstructed by revoking the sensationalism. Rather, the same tropes are hidden behind the depiction of normality in everyday life and show that centenarians, no matter how they act, are depicted as role models for aging.

Despite fundamental differences in audience and approach, the short documentary "A Sunday at 105" and Macklemore's music video share certain similarities having been made by young relatives of the centenarian presented. They both portray one day in the life of a female centenarian, they both deal with issues of physical fitness, independence, and sexuality, and they both contribute to an archetypal imaginary of extraordinary 'old' age. One major difference between the videos, however, is that "A Sunday at 105" lets its centenarian speak. As opposed to Helen, Aldéa Pellerin-Cormier gets to answer questions and thereby introduces herself to her audience. However, she replies solely to questions she is asked by her great-grandson, giving him the agency over the general narrative. Yet, as she—if we assume the answers are not scripted—gets to reply herself, there is a very basic form of agency on behalf of the centenarian in this documentary.

A large portion of this chapter looks at the way Pellerin-Cormier is portrayed in terms of age within this documentary; therefore, it is interesting to see what the audience receives from this clip. *YouTube* provides viewer comments that indicate how the video is perceived by its audience. Words that are recurring throughout the comments are "wisdom" and "cute" (M L.; Petit Phantome). While this description shows that a lowered sense of performativity does not necessarily lead to a negative view on the centenarian, the concepts mentioned tie into positive stereotypes of 'old' age. However, reading this documentary against the grain and inquiring about Pellerin-Cormier's representation from a cultural, social, and biological angle, provides a more multifaceted image of extraordinary 'old' age than these comments suggest. On the other hand, the comments are an indicator that expectations about extraordinary 'old' age are deeply rooted within society, keeping people from taking a second look and asking questions about what they have seen.

This chapter looks at the way Pellerin-Cormier is framed and frames herself as an extraordinarily 'old' person. Therefore, I discuss the way she is portrayed through the juxtaposition of her institutionalized, outward, physical, and behavioral age. I focus especially on her femininity as well as her independence in order to argue that she is fabricated into a model centenarian. Thereby, the documentary shows, in a more subtle imaginary of a centenarian than Macklemore's music video, the dream of aging well. Centenarianism, in case of Aldéa Pellerin-Cormier, is portrayed as not necessarily easy but still as a desirable achievement. Unlike other representations of centenarians, this one offers a rather raw view on life after turning 100,

yet, it still works to take away younger people's fears of growing 'old' as well as the fear of an aged population. From Pellerin-Cormier's perspective, the centenarian paradox crumbles, as she does not always describe her extraordinary age as positive. This makes it all the more interesting that the framework of the documentary suggests the desirability of extraordinary 'old' age. By looking at the way especially physical age is portrayed, I will point out that in order to become a role model of aging, a centenarian needs to be set apart from the 'old' in ways that go beyond behavior. Opposed to Helen, behavioral age here is not a determining factor, because Pellerin-Cormier descriptions of her every day life are often deeply connected to the 'waiting room' of 'old' age. Although this may not be her own choice—raising questions of care and isolation in general—it appears that the makers of the documentary feel the need to compensate this lack of behavioral youth by emphasizing physical fitness.

### **3.1 Music, Setting, Camera: How the Documentary 'Makes' the Centenarian**

This subchapter deals with the way filmmaking techniques within "A Sunday at 105" work in order to create an image of Aldéa Pellerin-Cormier as a centenarian and a role model of aging. Erika Balsom and Hila Peleg describe documentary film

not as the neutral picturing of reality, but as a way of coming to terms with reality by means of working with and through images and narrative. And beyond merely representing, reflecting, or helping to comprehend what exists, documentary can produce reality and thus influence beliefs, actions, events, and politics. (13)

It is thus crucial to understand that what the audience gets to experience in "A Sunday at 105" is not considered to be a 'truthful' or 'authentic' depiction. Rather, it is the attempt of its creators to come to terms with the everyday life of a centenarian. In that sense, it can be assumed that the director himself is so much in awe about his great-grandmother's extreme longevity that he needs the medium of documentary to help him make sense of the phenomenon. By this process, he in turn creates an image that he sends out into the world for his audience to make sense of it themselves. In this regard, documentary does not appear to be different from other forms of narratives. However, in this context Balsom and Peleg point to a very important factor: Documentary film intertwines narrative with images. The story that is told does not only consist of the centenarian's spoken word but also of various images that focus on certain points by use of camera angle and width. Moreover, the message of the documentary is supported through music. The entire clip is accompanied by changing background music which has a significant impact on the mood conveyed within the scene. I will therefore analyze selected scenes

in terms of images, setting, and music, as well as the overall structure of the film to argue that these techniques of filming the documentary work toward depicting Aldéa Pellerin-Cormier as a model centenarian. This model centenarian is a religious family person who can take care of herself without imposing too much on others. Furthermore, she is able to speak for herself and has agency over her actions and words. Thereby, the documentary creates a meaningful ‘reality’ about centenarians for its audience.

The first speech act<sup>1</sup> of the documentary does not initially work to introduce Aldéa Pellerin-Cormier but rather to introduce her relationship to her great-grandson. The audience hears a voiceover of him asking, “Grandma, what do you think of me making a film on you?” to which Pellerin-Cormier replies giggling, “using your Granny to make money! Naughty boy” (00:12-00:21). This short exchange dives right into the politics of autonomy and agency. The audience is told that it was not the centenarian’s idea to make this film. This again points to the idea of relational autonomy and suggests that without the initiative of the great-grandson, the centenarian would not have told her story in the first place. Moreover, by replying in an ironic tone, she implies the absurdity of thinking that making money could be her great-grandson’s agenda. The fact that Léger feels the need to address the issue of agency and the commodified centenarian at the beginning of his documentary reveals that he is aware of these mechanisms. It shows that there is an ever-present question of commodifying extraordinary age when it comes to the stories of centenarians. As previously mentioned, this documentary is also not free from these questions, as it was a tool to initiate Léger’s career.

As ironic as it may be portrayed, there might thus be a grain of truth in Pellerin-Cormier’s comment. However, the statement shows that Pellerin-Cormier is asked and, even if it remains implicit in her statement, gives some kind of informed consent to filming the documentary. Connected to the idea of informed consent, Couser points out that “the cardinal approach to biomedical ethics known as ‘principlism’—respect for autonomy, beneficence, and justice—seem pertinent to the sorts of life writing [he discusses]” (*Vulnerable Subjects* x). These same principles are also applicable to narratives of extraordinary age(ing). In this instance, Léger aims to inform his audience that he respects Pellerin-Cormier’s autonomy by showing that his great-grandmother is aware of the situation she is put into. According to Tom Beauchamp and James Childress, who established the four biomedical principles, autonomy is based on ‘informed consent’: “[S]ince the mid-1970s, the primary justification advanced for requirements of informed consent has been to protect autonomous choice” (121). Léger is not only aware of the ethical pitfalls he has to

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1 As Aldéa Pellerin-Cormier is Quebecoise, the documentary is filmed in French. In order to ensure a homogenous reading experience, I will quote from the English subtitles provided in the video.

avoid but also offers his audience an insight into the consent process itself. That is, of course, only if the entire sequence is not scripted and artificially made in a way for it to appear to be a consensual process.

Thinking back to Bolsom and Peleg's statement that documentary does not depict reality may also suggest that the dialogue on consent presents the director's attempt to make sense of the politics of agency and voice within his own work. Assuming that he does not want to exploit his great-grandmother, it must be difficult for him not to intertwine his own voice and imagination of the story with what the subject actually has to say. Reading the scene as an attempt to make sense of a reality then provides a new perspective on questions of agency. According to that reading, Léger creates a reality in which his great-grandmother has agency over the story because he is trying to come to terms with the agency question himself. Whether or not this happens is impossible to detect, yet, it does not change the fact that there is a need to address issues of agency in the first place. The centenarian is thus established as an autonomous human being with agency who gets to tell her own story.

Whereas the first dialogue of the documentary sets the tone in terms of agency, the background music works toward establishing the general mood of the video. By adding music, the film does not only become more pleasant to watch, the music also contributes to the message of a particular scene. John Fisk, for instance, claims music to be one of the "codes of television" which are "rule-governed systems of signs, whose rules and conventions are shared amongst members of a culture, and which [are] used to generate and circulate meanings in and for that culture" (1275). In terms of music, it is a common perception in the Western world that minor chords contribute to a rather 'sad' sound. Moreover, there are tunes connected to events, moments, or feelings that are shared within a certain culture. In the beginning of the documentary Pellerin-Cormier is shown going about her morning routine, including getting dressed, washing her face and putting on make-up (00:24-00:17). These images are accompanied by an upbeat tune that sounds like it could have been composed for a children's program. This music appears at the beginning and at the end of the documentary, setting the mood in a light, conversational way. It indicates that extraordinary 'old' age should not be taken overly seriously. Consequently, the music could be read as a means to overcome the stereotype of 'old' age as an era of gloomy decline.

Pellerin-Cormier putting on make-up in this early scene, indicating that this is her normal, every-day behavior, connects back to Helen's attention to her outward appearance. No matter how 'old' a person—or, more specifically—a woman is, trying to enhance one's outward appearance seems to be mandatory, although, as discussed earlier, the female aged body is not regarded as desirable in the first place. This scene may then either be a means to overcome these stereotypes or a continuation of midlife practices that could be attributed as mere habit. In any

case, this scene shows that Pellerin-Cormier does not conform entirely with being put away in the 'waiting room' of 'old' age and rather still acts according to social expectations concerning her gender role, rather than her age role. This is comparable to the portrayal of Helen in "Glorious." Both women cannot alter their outward appearance in a permanent way, but they both use non-permanent tools to supposedly enhance their looks.

Whereas using make-up is a purely visual tool for human enhancement, the documentary also shows Pellerin-Cormier engaging in her workout routine (01:13). Physical activity serves the purpose of staying in shape, both visually and physically. The scene shows that this documentary uses familiar tropes when it comes to describing a centenarian. The centenarian is able to engage in physical activity, and, at the same time, shown as willing to work for it. The documentary specifically points to physical age in connection to institutionalized age by including a voiceover of the centenarian speaking about her age while she is working out. Here, the documentary hints at the idea that it is not necessarily predetermined by genetics who lives the longest but that a long and healthy life is hard work for the individual. Accordingly, the fact that Pellerin-Cormier is shown working out also implies that in order to get to the goal of turning 100, one needs to do the same. If one does not, one will not reach the goal and have thus failed at the game of aging. In this instance, the documentary ties into a successful aging paradigm by promoting neoliberal ideas of extraordinary 'old' age as achievement that is left to individual responsibility.

This scene serves yet another purpose, besides making sure the audience understands the need for physical fitness in order to achieve extraordinary 'old' age. After reminding us of her age, Pellerin-Cormier continues by saying "[w]atch it, I'm gathering speed" (01:19), indicating the humor of the statement by laughing. Here, the centenarian works as her own comic relief, showing that, even at 100, she is a humorous person. In this instance, she herself plays with the juxtaposition of age categories, that is, she is fully aware that the rather ordinary activity of using an exercise bike becomes an extraordinary one when looked at in connection to her institutionalized age. The humor thus arises from the fact that she knows that she is not the fittest or fastest person anymore, yet, she still tries. The centenarian hence subverts stereotypes of 'old' age, by not getting frustrated by the restrictions that the biology of her body present. Consequently, the scene can also be read as one of these rare narratives that accept the biological changes of aging without demonizing them. At the age of 105, it appears to be allowed to be a little slower. This in turn partly revokes the ever-present after taste of successful aging in centenarian narratives.

The two readings of the scene reveal two different perspectives on age(ing). Léger, the middle-aged director uses the technique of a voiceover to remind the audience of his great-grandmother's age while showing her during physical activ-



ity. This speaks to the 'young' wish that the restrictions of the aged body are not as severe as many decline narratives would suggest. At the same time, however, it reinforces images of successful aging. Pellerin-Cormier, on the other hand, shows through her joke that she is well aware of the restrictions of the aged body and content with them, offering a perspective that questions imaginaries of the biology of aging that have been established in Western culture. What this documentary drives home, then, is that it is always exceedingly important to understand who gets to speak. In this connection, Karin Lövgren argues that "it does matter who conveys a message and who has the right to define and verbalize. As far as aging as an asymmetric power relationship goes, one of the problems is that it has mainly been others who have spoken for, in this case, older people" (51). Although the documentary lets the centenarian speak herself, it is often, as the following subchapters will continue to show, the way her speech acts are entangled with images and music that alter the meaning. This then reveals the underlying power structures within this documentary. While Pellerin-Cormier gave her consent to filming in the first place, the ways in which filming techniques might alter her voice are generally beyond her control.

This observation, in turn, raises numerous questions about the issues that we do need to address within narratives about 'old' age. Ricca Edmondson reminds us that it is essential to find meaning in later life (102). But who is to decide what meaning means and what renders a life meaningful? Can there ever be narratives of 'old' age that neither buy into either the successful aging nor the decline paradigm? In that connection, Lily Nosraty argues that "definitions and models of successful aging attempt to prescribe how people should age rather than understanding how elderly people as a heterogenic group define the process themselves as they age" (51). This argument refers back to the discussion of voice within narratives of extraordinary age and indicates that the only way to move away from binaries, such as decline versus progress, is to focus on the individual and listen to individual stories. Yet, how can a co-produced narrative be an individual story in the first place? And how can the creators of such narratives bridge the gap of different experiences of a middle-aged director and a centenarian subject? While this particular narrative tries to navigate this very fine line, sometimes conflicting perspectives lead to contradictory moments within the documentary.

Besides emphasizing her physical fitness, the documentary also focuses on Pellerin-Cormier's outward age. In fact, there are many scenes that highlight her as extraordinary 'old' through outward appearance. For example, there is a lengthy close-up shot on the centenarian's hands during an interview (03:41). Due to popular belief, a person's hands are the body parts most likely to reveal their 'real' age. Shelly Emling writes in the *Huffington Post* that "[a]lways exposed to the elements, your hands probably give away your age more than any other body part." Of course, this article cannot be regarded as a reliable scientific source, yet, it shows how be-

liefs about outward age are fostered in broader society. It may thus be no coincidence that Léger chooses this close-up shot onto his great-grandmother's hands. If hands are perceived as the most reliable indicator when it comes to a person's age, the documentary shows us, what a centenarian's hand looks like. In this scene, there appears to be no filter or anything working in order to make Pellerin-Cormier appear younger. In this instance, I argue, this is because the spoken narrative goes along with the images. In this particular part of the documentary, the centenarian speaks about the moon landing and how going to space influenced humans' perception of time. In order to address such philosophical questions of time, there needs to be a certain amount of wisdom, a quality that is often expected from elderly people with a great amount of life experience.

Furthermore, the visual emphasis on her extraordinary 'old' age supports the claim she makes about temporality. She asserts that by going to the moon, humans "broke the stars of time. Now time is different" (03:41-03:44), meaning that they did something so extraordinary that it seems to be out of a futuristic sci-fi movie. At the same time, however, she herself 'broke the stars of time' by living much longer than the average person. Consequently, Pellerin-Cormier's extraordinary 'old' age is implicitly linked to the changing of time and its perception. The centenarian is a role model not only for a healthy lifestyle and extreme longevity; she is also what scientists such as Aubrey de Grey look toward when they try to slow down the aging process. In that sense, then, slowing down aging or living longer means slowing down time itself. Connecting her outward age to temporality offers a new perspective on centenarianism: as centenarians have broken the stars of time, it really does not matter what they look like. They have earned the right to be 'old.'

Pellerin-Cormier is frequently depicted laughing and joking which suggests that her great-grandson knows of the joys she has in life. This depiction can be read as an attempt to present extraordinary 'old' age as meaningful and fun. Her bubbly personality and constant giggles, on the other hand, may remind the audience of a teenager—especially since her fits of giggles increase when she speaks about sexuality—juxtaposing her institutionalized age with her behavior as well as contrasting her outward age with her behavior. Her personality opposes the idea that she might be unhappy with her life and longing for the past. Rather, she appears to be a lively person who enjoys herself in the moment. The juxtaposition inherent in these scenes can be read as a criticism of lively behavior being reserved for 'young' people. Seeing a giggling grandmother may strike people as something extraordinary whereas it should be normal at all ages to engage in laughter and vitality.

Through filming techniques and music, the centenarian is framed as an outgoing, bubbly person who enjoys life. Yet, the documentary seems to constantly navigate between the perspectives of Pellerin-Cormier herself and that of the director, giving a twofold imaginary of extraordinary 'old' age. This form of narration

adds to the depiction of the complexity of (late) life. There is no black and white and there is, at no age, a perfect life without problems, desires, and hopes. Léger takes the reality of his great-grandmother combined with the reality he assumes about 'old' age in general and presents his audience with an elaborate thirteen-minute piece that tries to make sense of the complexities of extraordinary 'old' age. Nonetheless, the topics addressed in the documentary are similar to what can be usually found in articles on centenarians. There is generally the underlying question of "how did you do it?" and "how can I get there as well?" This first impression, gained through looking at selected scenes through the lens of representation and filmmaking, deepens throughout the documentary as Pellerin-Cormier takes the audience through her thoughts and her experiences.

### 3.2 Passing on Knowledge: The Centenarian's Wisdom

Besides portraying Pellerin-Cormier's physical ability by focusing on her workout routine, the documentary emphasizes her mental abilities. Marlene Goldman argues that "[t]he current 'Age of Alzheimer's' is . . . characterized predominantly by fears of an epidemic of terrifying proportions" (4). In order to counter this fear, it appears important to show that Pellerin-Cormier is able to respond and speak to her audience about her experience. At the same time, the centenarian's ability to retell her life's story, in connection with her extraordinary 'old' age, seems to elevate centenarianism to a special position within the context of 'old' age. This framework becomes important in many centenarian narratives, as the centenarian is often framed as a beacon of wisdom, therefore needing their memory to draw from their vast life experience. This expected wisdom, on the other hand, is also a general stereotype of 'old' age. Because 'old' people have experienced a lot, they are expected to have insights into life itself that 'young' people cannot have come by, yet. The older a person, consequently, the wiser they are supposed to be. In that sense, centenarians are presumed a gift to humanity, as they can share the wisdom and experience of more than 100 years. This following section deals with the moments in the documentary when Pellerin-Cormier is presented as a wise person and is implicitly or explicitly asked for advice. These expectations of wisdom do not always go along the lines of the centenarian's self-perception and indicate how the fabrication of centenarians, or generally all age groups, goes beyond the power of members of the respective age group.

First of all, the documentary makes a stark contrast between wisdom and knowledge. In that connection, Pellerin-Cormier explains: "I have no education. I went to school for two days. The teacher wasn't there. I didn't learn much. What I know, I learned on my own. I'm not knowledgeable" (03:00-03:35). This scene emphasizes again that she comes from a different time. When she grew up,

education, especially for girls, was not regarded as important. More significantly, the scene makes a claim about the centenarian's intelligence. Pellerin-Cormier's statement is presented as a voiceover in the documentary, accompanying images of her reading the newspaper. Although she thus has no formal education, she is literate and eager to stay up to date with current events. Presumably, she was able to teach herself to read, a fact that points to great cognitive abilities and diligence. This foundation is needed in order to give merit to her musings about the world. Her experiences and what she can teach others about life becomes all the more important because she is an intelligent person. A general intelligence or interest in one's surroundings is portrayed as more important than any formal knowledge.

Consequently, formal knowledge is not needed to be a wise person because the wisdom sought of 'old' people does not need knowledge. Indeed, 'old' people who try to ingrain a great deal of knowledge and expertise into their statements are frequently socially sanctioned. Psychologist Scott King, for instance, traces the persona of Sister Jean who rose to fame as she served as the Loyola basketball team's Chaplain at the age of 98. Treated more like a mascot than a person, Sister Jean was well-liked until she offered her opinion on college basketball—a field she has great expertise in. After sharing her thoughts, she was faced with derogatory and ageist comments, showing that she can serve as a mascot but that she cannot have an opinion (King). Like Sister Jean, Aldéa Pellerin-Cormier is welcome to be wise about life's experiences, yet, she is not supposed to be very knowledgeable. By establishing this from the very beginning, the documentary portrays the centenarian as harmless to society: She wants to help, but she is well aware that she can only contribute to certain areas. These areas include lifestyle questions more than anything else. The centenarian accordingly enlightens the audience on her ideas about religion, diet, and the fear of death.

As the guide to a healthy long life *Celebrate 100: Centenarian Secrets to Business and Life* suggest, "faith" is one of the key 'secrets' of centenarians (Franklin and Adler 139). Accordingly, Pellerin-Cormier is presented as a deeply religious person. Her home is full of crosses and Virgin Mary statues, and she is shown praying. Further, the only scene of the documentary showing her outside her house depicts her putting up a Virgin Mary statue in her backyard. This is also a rare scene where she is not shown alone but accompanied by her great-grandson. Religion and spirituality here imply freedom and community. In her religion, she is not alone and therefore able to escape the loneliness of 'old' age. Again, the documentary does not only work with images but also with music. During this scene, the melody changes into an instrumental version of Billy Joel's "And So it Goes," a well-known love song about the endlessness of love but the ever-present possibility of changing partners. Billy Joel sings in the opening verse "in every heart there is a room / A sanctuary safe and strong / To heal the wounds from lovers past / Until a new one comes

along” (00:25-00:50). This sanctuary, for Pellerin-Cormier, is her faith. As long as she believes, the world can come and go, because she has God.

Moreover, the emphasis on religion speaks to a certain expectation of morals and values. Religious, and in the Western world especially Christian people, present themselves in accordance with certain commandments that stir their morals and supposedly demand a certain amount of altruism and charity. Connecting the centenarian to these characteristics stages her as a person who deserves to live to 100. Being a good Christian in this instance goes along with being a good centenarian. At the same time, the narrative suggests that in order to achieve the goal of centenarianism, a person does not only have to live well and healthy but also be a good person. Religion and faith are introduced as means to a good life and also as a means to achieve extreme longevity. This message is backed by numerous studies tracing a correlation between longevity and spirituality. Ana Sandoui writes that “[r]esearchers led by Laura Wallace, a doctoral researcher in psychology at the Ohio State University in Columbus, have conducted two studies whose results show that religion could give believers a 4-year longevity boost.” These studies, among many others, suggest that religious people generally live longer. It is thus part of the centenarian’s wisdom to be a spiritual person because this is the only way to lead a good and long life.

The above-mentioned scene portrays this wisdom without having Pellerin-Cormier speak while putting up the statue. Rather, it is supplemented by her own voiceover, as she comments on people’s strive for ‘truth’ and knowledge. She claims that people want to be “smarter and smarter... smarter than God” (04:20). It is seems important to her to convey that scientific hybris is not desirable. She claims that there are certain phenomena better left alone, an attitude that provides a human being with a certain ease when it comes to the big questions in life. Instead of wondering about the ‘ifs’ and ‘buts’ of the world, she puts her faith in the hands of God and therefore worries less.

Despite giving advice on faith and knowledge, Pellerin-Cormier is supposed to provide wisdom when it comes to her diet. Although, she never explicitly tells people how to act, Pellerin-Cormier talks about what she eats, as well as shows the audience how she behaves. Voluntary or not, the documentary gets the centenarian’s wisdom, no matter if the centenarian herself thinks she has it. For instance, she casually mentions “I love lobster, I’ve eaten a lot of it” (10:08-10:10). This sort of food advice is as common in centenarian narratives as the emphasis on physical ability. The main interests of ‘young’ people seem to be questions such as ‘What do I have to eat?’ and ‘How much do I have to move in order to live to 100?’ The lobster, in this instance does not only become a symbol for a model diet but also touches upon issues of physical ability. Pellerin-Cormier does not only say she likes lobster, she is also depicted taking one apart and eating it (10:08). This imagery emphasizes that she has the necessary strength and motor skills to do so. Her eating habits

thus have not only kept her alive until the age of 105, they have also kept her strong enough to pull apart a lobster.

The centenarian becomes an expert on dietary needs. Since dietary choices clearly have an effect on a person's longevity, it makes sense to inquire about these issues. In that connection, molecular biologists Burtner and Kennedy write that "[c]oncomitant with longer lifespan, dietary restriction delays the onset of a range of age-associated pathologies in invertebrate and mammalian models" (567). Interestingly, however, people seem to not only turn to science in order to find out what diets exactly are supportive of a long and healthy life, rather, they put their faith into firsthand accounts, no matter how contradictory they might turn out to be. Why should the public ask a person who has studied nutritious needs on paper, when they can listen to a person who has healthily made it to extraordinary 'old' age? In that connection the lobster scene also points to the fact that no matter what the centenarian says, it is perceived as wisdom. Quite possible, Pellerin-Cormier simply wanted to declare her love for lobster without indicating that its consumption is a reason for her longevity. The audience, on the other hand, is inclined to read it as advice, simply because this is the way narratives about centenarians are structured.

At the end, the documentary works with another common trope of centenarian narratives and food. For her evening routine Pellerin-Cormier takes a shot of liquor, pauses and comments, "that's strong" (12:43). At the end of the day, the centenarian is no health guru; she, too, drinks alcohol and enjoys the little treats in life. She does so moderately, but the good news conveyed here is that one does not have to be a saint after all to become a centenarian. These 'feel-good' factors, the little extraordinary things that nobody would associate with longevity, are an integral part of narratives about centenarians. There is, for instance, a centenarian who attributes his longevity to drinking one glass of red wine every day (Somper); another claims her secret to be eating chocolate (Pawlowski). In the vast landscape of the internet, there is virtually no 'secret' to longevity that one could not find, giving every single person a justification for an unhealthy guilty pleasure. This presentation of centenarianness decreases the notion of sacrifice needed to supposedly age successfully, suggesting that anybody can do it. Ultimately, depictions as such, while, on the one hand, pointing toward the little pleasures in late life, are, on the other hand, always also prone to increase the notion of supposed failure of those who do not manage to age in the same manner.

The wisdom Pellerin-Cormier is asked to provide is not restricted to dietary needs and spiritual guidance. She is also interviewed about how to deal with the aging process, in this case the only area, that she does have a natural expertise in. She has experienced age(ing) through all the life stages and can give the audience a firsthand account of what it felt like for her. Thus, her comments on her own experience as a centenarian become one of the main values of this documentary. For

instance, she comments on the world she lives in by saying “[t]he world turns fast, very fast. That doesn’t bother me, I travel at the same speed” (08:28-08:35). This indicates that she can keep up with the world and therefore with ‘young’ generations. As she can keep up with the fast movement, she emphasizes that she can still be a part of everyday life. In that sense, she refuses to become isolated from society or become invisible.

This visibility is also granted through the documentary, of which she is the subject. She is made visible by her great-grandson, a mechanism only possible because she is not just ‘old’ but extraordinarily ‘old.’ Nevertheless, with her statements, she herself works against the label of invisibility and social exclusion. Against popular belief, she can keep up with life and can therefore still be a valuable part of society. This take on extraordinary ‘old’ age is mirrored in her wish to go to the moon someday (03:26). Pellerin-Cormier is not only able to keep up; she also wants to go further than most people have. She quite literally tells her audience that she is still willing to reach for the stars. In these instances, the centenarian emphasizes that she is not a creature of the past but that she very much lives in the here and now, with ambitions for the future.

What is interesting about these statements, however, is that they not only provide insight on how to get to extraordinary ‘old’ age but also on how to live in late life in general. On the one hand, this can be read as directed to ‘old’ people who are trying to escape the invisibility and presumed meaninglessness of their age group. On the other hand, these scenes also address ‘young’ people who might be scared of growing ‘old.’ Ultimately, the documentary provides insights into Pellerin-Cormier’s wisdom to strengthen a neoliberal stance on aging: If you manage to live a life as good as she did and does, you might be able to remain a viable part of society in later years, as well.

As much as Pellerin-Cormier is focusing on the present or even the future, the documentary shows that she is aware of her limited remaining life expectancy. Therefore, it hints at questions of how to cope with the knowledge that one may die quite soon. The centenarian appears to be well aware of that fact as she states: “I’ve little time left in this world” (12:06). Although this statement is accompanied by sad music and the centenarian’s rather sad facial expression, she generally appears to be content with her situation, especially because previously in the documentary she stated “[a]fraid of dying, at 105? Oh, come on, I’m old enough to die” (06:50-06:55). She is hence not particularly looking forward to the day she will die but she has made her peace with it. She knows that she has had an exceptionally long life and is grateful for that. Here, the sense of temporality ties in again: she is aware of the experiences she has had and understands that her lifespan has been long enough. The wisdom that it is okay to die after a long and fulfilled life goes against the attempts of scientists to prolong life or find a ‘cure’ for aging. As a person who spent 105 years on this planet, Pellerin-Cormier might have insights

into longevity that the 'young' scientist, so afraid of aging and dying do not yet have. This also goes along the lines of the centenarian's claim that scientists are trying to become smarter than God and are thus meddling in affairs that they cannot possibly understand.

For Pellerin-Cormier it seems to be more important to have led a good and fulfilling life than to go on forever. She contemplates, "I've had a nice life. No complaints there. I wasn't too mischievous. I worked. Working... was my forte. Working and Praying . . . There isn't much I can say I didn't like" (11:11-11:59). She tells the story of a life well lived, not only in terms of happiness but also in terms of contribution to society. She again emphasizes her faith and adds to it her nature of being hard-working. The wisdom that can be read into this suggests that once a person has led a good life, it is okay for this life to end. Generally, the entire documentary points to Pellerin-Cormier's good life, faith, and hard work having led to a great and happy family who will carry on her legacy, after she has died. In that sense, the centenarian does not only escape the invisibility of 'old' age, she also does not have to fear oblivion after death. Knowing all that, she enjoys her remaining time on earth without having to fear death.

Interestingly, Pellerin-Cormier is given the chance to comment on politics, and, as opposed to Sister Jean, is allowed to have an opinion which is based in specific knowledge. Yet, she does so very timidly, without any concrete statement. Furthermore, her political criticism is directed toward the U.S., not toward her home country, Canada: "Americans are all right but maybe they go too far to their detriment. They've gone too far into the affairs of other countries" (04:00-04:12). From a perspective outside the USA, her comment appears uncontroversial, as she merely echoes common assumptions about U.S. politics. Other than Sister Jean's comment on basketball, Pellerin-Cormier's brief excursion into politics is hence uncontroversial and therefore remains unsanctioned. The same goes for her own voting practices: "I never voted conservative. I always voted liberal... Voting conservative is a mortal sin" (09:35-09:47). Here, the centenarian gives a fairly direct advice on how to vote. Yet, she does not do so in a political setting but from the safety of her own home. Furthermore, she does not engage in a political argument. She merely states her political preferences and does so quite vehemently. Yet, she is given the stage to voice her opinions and according to the comments, this does not affect her likability: The user Russel Loomis writes that "[he] like[s] her even if she is a Liberal and [he]'s a sinner." Whereas Sister Jean, as an almost centenarian, was sanctioned for having an opinion, as a centenarian, Pellerin-Cormier is able to harshly criticize people about their political preferences and still be well-liked.

Ultimately, Aldéa Pellerin-Cormier is staged as a person who has to share wisdom about life in general. While her own opinion on whether the audience can learn valuable lessons from her may differ, the documentary continuously points to her as a wise role model. It is because of her extraordinary 'old' age that she can-



not make a simple statement about her preferences in diet, exercise, or worship without it appearing to be advice for a long and healthy life.

### 3.3 Femininity, Sex, and Gender in Extraordinary 'Old' Age

Besides giving insights into the everyday life of a centenarian, "A Sunday at 105" touches upon topics such as the connection of extraordinary 'old' age to femininity, sex, and gender. As previously mentioned, the female aged body is sanctioned due to lack of attractiveness. In that connection, Ateret Gewirtz-Meydan and Liat Ayalon explain, "older people are often excluded from the discourse on sexuality and are considered asexual. . . . This stereotypical view of later-life sexuality is termed 'sexual ageism'" (648). This 'sexual ageism' may then be the reason that in Macklemore's music video sexuality in extraordinary 'old' age is depicted but frowned upon by younger generations. In "A Sunday at 105" there are numerous statements concerned with sexuality, yet, Pellerin-Cormier appears to distance herself from the idea of having a partner, a romantic relationship, or just sex. Accordingly, she behaves appropriately, according to her age, in a broader cultural context. Hence, it is interesting that the documentary would touch upon these issues in the first place. After all, 'old' age and sexuality do not go together well in popular consciousness. This subchapter is dedicated to tracing the way the documentary portrays femininity and sexuality in extraordinary 'old' age and to discuss how this portrayal works to (de)construct age categories.

One very crucial point when talking about gender relations in "A Sunday at 105" is certainly the absence of a partner. The audience may assume that there once was a husband who might have passed away—a thought quite possible, when considering the higher female overall life expectancy. The one time Pellerin-Cormier mentions a husband is when she talks about how she used a huge shell she would blow into to signal him to come home from the fields for food (00:09:00-00:09:06). This suggests that their relationship was defined by traditional gender roles of a working husband and a stay-at-home wife. Yet, apart from this scene, where he is only mentioned in passing, the husband remains absent. This absence of a partner would raise questions in many life stages, yet, in extraordinary 'old' age, the audience is invited to assume that there once was a husband who is now dead. In that connection, it is interesting that the documentary in general does not touch upon the high probability that the majority of Pellerin-Cormier's peers have passed away. As opposed to many other centenarian narratives, the question of how to deal with grief is not addressed in this documentary. This is one more aspect that adds to the construction of her extraordinary 'old' age as a phase of joy and meaning, rather than grief and loneliness.

As for her current love life, Pellerin-Cormier comments as follows “I’m not doing anything on earth, nothing worthwhile. I don’t even have a boyfriend” (07:00-07:16). This statement indicates that the centenarian connects her self-worth to man in her life. However, although the two sentences follow each other, there is a significant pause between them. Furthermore, they belong to different scenes of the documentary. While they are both presented as voiceover, not a direct interview, the first part is accompanied by an image, where Pellerin-Cormier looks like she is falling asleep and followed by a sequence, where she is desperately trying to keep her eyes open (07:01-07:10). This underlines that she is not doing anything worthwhile, as she can barely stay awake. Looking at this scene individually suggests that the documentary here moves away from its extraordinary ‘old’ age as meaningful pattern and establishing a narrative of decline, after all. Throughout the documentary, showing the biological realities of the centenarian body seems not problematic. Through the connection to the statement, however, it depicts the aged body as worthless in society because it cannot do anything that would be considered to be useful.

The second part of the statement, her not having a boyfriend, is accompanied by a camera shot of Pellerin-Cormier—or what we assume to be her—in bed, sleeping (07:16). Taken separately this voice-image connection suggests that, like it is socially acceptable, she only uses her bed for sleeping. While looked at separately, the two parts of the statement in connection to the images going along with them suggest that the centenarian lacks worth and that she is not sexually active. In combination, however, they suggest that the centenarian connects her self-worth to a man, an idea that seems ironic, thinking back to the fact that she does not even mention a partner as a significant part of her life. Conclusively, she might not have needed a man in order to live a meaningful life. Finally, the editing of the film and the images provided here are crucial for the analysis. After all, the audience cannot know whether Pellerin-Cormier did make these two statements successively. Maybe, here the director, who also is the centenarian’s great-grandson, flees into wishful thinking, avoiding imagining his great-grandmother as a person with sexual desires. Following this reading, there is a connection between “A Sunday at 105” and Macklemore’s music video. In both instances, a male descendent denies sexuality to a female centenarian and thereby contributes to ‘sexual ageism.’

However, the way Pellerin-Cormier is framed here does not indicate a wish for romance in late life. If she had a boyfriend, would she consider her life more meaningful? In that connection, Pellerin-Cormier continues saying that “[men] don’t excite [her] anymore” (07:20). The fact that the camera still shows her in her bed sleeping ties in with the assumption that the director wants to declare to the audience that his great-grandmother does not have a sex-life at all. The centenarian herself also makes it very clear that she might be interested in a companion but not in a sexual relation, as she chooses to say “excite,” not “interest.” Later life remains a

space that lacks eroticism for her as well. There appears to be little possibility to subvert social assumptions about sexuality that are connected 'old' age. Whereas centenarians are portrayed as beyond 'old' age in many aspects of their existence, being imagined as sexually active seems to be an uncrossable border.

At another point in the documentary, Pellerin-Cormier speaks about her past relation to sex and gender roles. She explains that "[w]hen I was young, I wanted to be a man. That was my wish, because I felt men didn't work very hard. But once I grew up, I no longer wanted to be a man. Sex..." (07:33-07:46). After saying this, she starts giggling and waves her hand as if to brush away the last part of her statement while shyly looking away from the camera. Then she says "get out" and laughs (07:47-07:50). The belief that men do not work hard presents a contradiction to common stereotypes of only work outside of the domestic sphere being hard work. In that sense, Pellerin-Cormier is presented as a pioneer in terms of gender imaginary, pointing to the fact that women indeed work very hard, despite the fact that their efforts often remained unseen.

Considering the second part of her statement shows that apparently sex had something to do with her change of heart when it comes to her preferred gender. She does not elaborate further on what she means, however, her statement can be read as her changing her mind from wanting to be a man toward wanting to be *with* a man, especially when thinking about her hand gestures and the 'get out' at the end of the scene. Possibly, she cannot imagine having sex as a man and prefers what she considers to be the female part of the act. Her accompanying hand gesture, on the other hand, might also suggest that sex is something that she was never really interested in or at least something that she does not want to elaborate on. This might be due to her Christian beliefs, her general shyness, the familial relation to the interviewer, or just her acquired gender role as a woman telling her that it is not acceptable to speak about her sexual desire publicly. The following conversation between her and her great-grandson supports this reading: Léger asks, "What did you do under the covers?" to which she replies "Slept" and chuckles (08:02-08:08). This almost reminds the audience of a teenage girl who has had her first sexual encounters but is too shy to speak about them or knows that her family would not approve of her ever having (had) sex in the first place. It seems that, for the centenarian, sex is a taboo. Interestingly, she is thus placed back into adolescence behaviors. Her behavior does not conform with a confident woman but rather with a shy girl. Nevertheless, it is important to bear in mind that she did grow up in a different time, which might restrict her from confidently claiming her sexuality.

Ultimately, this scene denies the centenarian to break out of stereotypes of 'old' age in this very instant. Gewirtz-Meydan et al. describe that "key myths that have been conceptualized in relation to older people's sexuality include: a lack of sexual desire that accompanies aging; the physical unattractiveness and undesirability of older people, which is particularly evident in relation to gender" (150). In

terms of sexuality, the director as well as the centenarian seem to acquire a sense of conservatism and conform to the stereotypes prevalent concerning 'old' age and sexual desire. It is arguable that it may be possible for a centenarian to break free of stereotypes of 'old' age in many instances and become part of a new life stage. At the same time, it remains impossible to break free of gender stereotypes at the same time. As will be discussed further in chapter 4, the absence of sexuality is not as prominent in male centenarian narratives. Antiquated gender roles which imply that women are the object of desire rather than actively feeling it themselves may thus tie into the current representation of female centenarians' sexuality. This reading then shows how centenarianism influences the way a person is perceived in terms of age while stereotypes of gender remain in place.

### **3.4 Aging, Place, and Questions of Ability: (In)Dependence in Extraordinary 'Old' Age**

Besides speaking to questions of wisdom and sexuality in extraordinary 'old' age, "A Sunday at 105" also addresses one of the major issues connected to aging and late life in general: How does a person deal with the biological changes of the aging process? How does life change once a person is not able to live entirely independent? How is late life affected by loneliness and loss? As mentioned above, loss is never a concrete issue in this documentary, yet, the images depicting Pellerin-Cormier's ordinary life raise questions about her being alone for most of the day which, in turn, implicitly points to a loss of friends and family members. The documentary hence deals with questions of loneliness and care in later life that are ever present within the media or even in people's minds as there is a fear of 'the grey tsunami' rolling over society, overwhelming 'young' generations in terms of care capacities and finances. In that connection, Ulla Kriebner and Sally Chivers argue that most people will require some kind of care in later life, leading to a narrative that connects care homes with failure and living at home as success:

Whether in a nursing home, care home, retirement home, assisted living, or other form, institutional care for seniors offers a cultural repository for fears and hopes about an aging population. While people adamantly desire to age well at home, without making the big move to render their latter years more manageable, and policy makers play to that desire, apparently buoyed by how it offers them an opportunity to download the costs of care onto the family unit, the fact remains that many contemporary senior citizens will require institutional care, and some might even choose it. (17)

Pellerin-Cormier's narrative is one that ties into the desire to age well at home, as she is depicted as living in her own apartment, being at least partly indepen-

dent. The fear of having to leave one's home and move into a care facility seems to evoke fear amongst older people. This is, on the one hand, due to the obvious loss of independence and daily routines. On the other hand, these fears are increased through media reports demonizing life in these facilities. "A Sunday at 105," in that connection, presents an implicitly harmful message within the discourse of care, as it suggests that 'stay at home' care is easily possible and desirable.

Meaning in Pellerin-Cormier's life might thus be tied to the fact that she is living at home. Consequently, Chivers and Kriebnernegg continue arguing that "[w]hen the popular press is overwhelmed by negative, it is not just evoking fear about what each person's fate might be—a deep fear of physical change that could bring pain and restriction to the activities of daily living, not to mention raising the spectre of death" (19-20). Although the documentary does not actively paint care homes as something negative, it makes caring for the elderly at home look effortless and is thus harmful in two ways. First, it implies that the paragon of aging does not need a care home, because whoever ages successfully, can do so at home. This goes back to neoliberal ideas of self-improvement and a narrative of success versus failure. Second, it presents home care as something that is done effortlessly without portraying the care givers. The audience never learns about Pellerin-Cormier's support system when it comes to everyday life. This chapter will thus look at the way care, (in)dependence, and aging in place are portrayed within the documentary and elaborate on the implications this makes for a broader debate on health care issues. The model centenarian, I argue, has to live at home in order to function in their role as paragon of aging and take the fear of later life away from society. In terms of independence, their lifestyle or behavior is juxtaposed to expectations of a dependent elderly person. While contributing to this idea of the model centenarian, the depiction of Pellerin-Cormier's everyday life cannot be regarded as one of successful aging, as it is shaped by loneliness.

The documentary opens with a shot of a home, which—for lack of any other information—has to be Aldéa Pellerin-Cormier's house. Some cars passing by indicate that she does not live completely remote, yet peacefully and quietly. In accordance with the entire rest of the documentary's makeup, the setting could be described as utterly 'ordinary.' The general setting, however, invites initial questions about the centenarian's living situation. Does she live alone? What is the (aging) infrastructure like in this rather rural setting? Does she have access to a store, entertainment, friends? Unfortunately, these are all questions that are never directly addressed through the documentary. Hence, it appears that although the narrative can be read as a guidebook when it comes to questions of how to age well, it is not any help for people who are looking for care-taking models. This conforms to the idea that the centenarian needs to be constructed as a very able person in order to function as a role model.

Some questions are touched upon implicitly through the centenarian's statements concerning other topics. For instance, Pellerin-Cormier enlightens the audience in her daily routine:

When I wake up, I cross myself and that's how my day begins. I get dressed, I eat breakfast. If I have chores, I do them. Otherwise, I sit... and rock. I wait for lunch. When lunch comes, I eat and lie down again. When I've slept enough, I get up and sit down again. That's how I pass my time. (01:47-02:18)

In this quote, the centenarian again emphasizes her faith, as she starts every day acknowledging God. What is more interesting about her statement, however, is the way she describes her everyday life. There may be no other description more fitting than dull. It does not seem very desirable to spend most of the day sitting and waiting. This directly speaks to the metaphor of the 'waiting room,' especially when thinking about the fact that Pellerin-Cormier herself states that she is 'old' enough to die at 105. Of course, as mentioned above, this shows contentment with the finiteness of human life; on the other hand, it can be read as an implication that the centenarian spends her days waiting for death. The audience does not know if she ever goes out to meet friends or has any other activities on her daily schedule. After all, we are watching her on a Sunday, a day that for many people means to primarily relax. Yet, as a religious person, she is not shown going to church on a Sunday, implying that she is mostly confined to her home.

Her words, however, are contradicted by the images of the documentary. She is precisely not depicted sitting around, waiting. Rather, she is shown exercising, praying, watching TV, putting up a Virgin Mary statue in her backyard, and even playing cards with, what we can assume is her family, as one player calls her "Grandma" (10:52). Generally, this incongruence of word and action could be due to another discrepancy between awareness of self and awareness of others. Either the centenarian might feel that she is not doing anything but sitting and waiting when, in fact, she engages in a variety of activities, or she talks about her general day that may differ from what has been staged for the documentary. Maybe the only human contact she has on an ordinary day is someone, presumably her daughter, bringing her lunch (06:26-06:44). In that connection, Pellerin-Cormier's remark serves as a criticism of her limited abilities to engage with other people. In terms of activities, she seems to be completely dependent on her family. Loneliness, although the images of the documentary suggest otherwise, is thus implicitly presented as a major problem in extraordinary 'old' age. The audience does not get to know whether the centenarian has a community of friends to support her, and sheer statistics demonstrate that chances are high that her peers have passed away. Isolation can have tremendously negative effects on the human organism. The U.S. Center for Disease Control and Prevention explains that "[a]lthough it's hard to measure social isolation and loneliness precisely, there is strong evidence that many adults aged

50 and older are socially isolated or lonely in ways that put their health at risk” (“Loneliness”). In terms of aging, or even generally, loneliness therefore should be avoided. However, as Pellerin-Cormier is depicted as preferring to stay at home and to pass her days mostly sitting and waiting, the documentary implies that living in a nursing home would be a worse fate. The factor of being alone and isolated for most of the time is glossed over by the documentary and only traceable in certain statements by the centenarian herself. In that connection, images might trump her words with regard to the power of determination of the narrative. Consequently, the audience is inclined to believe what they see, a woman who frequently interacts with several family members and has a full schedule of activities.

In addition to the issues of loneliness and isolation, the documentary indicates that stay at home care is easy to handle for all participants. Elder care does not seem to be a problem in Pellerin-Cormier’s case. She is independent enough to do her chores and prepare her own breakfast. Furthermore, her house does not seem to have any special needs facilities, which indicates that she does not require them. Throughout the documentary, she seems rather mobile and self-sufficient. There is only the odd moment when she is shown falling asleep sitting up or when her great-grandson needs to support her walking in the garden that allow her to show weakness. All these signs of supposed weakness are treatable with relatively low effort and cost: if she needs to sleep, the easy solution presents itself in form of taking a nap. If she is unable to navigate the uneven ground of her lawn by herself, there is no urgent need for her to go out there in the first place unless someone is there to accompany her. These thoughts, although they present easy solutions to the arising problems, are of course highly problematic as they all suggest that problems are solvable by restricting the centenarian to certain areas and certain activities. These solutions only appear to be acceptable when not looking at the centenarian’s perspective, who is unable to do as she pleases. From the perspective of younger generations, however, it does not seem to be a sacrifice, as the solutions offered solve problems of elder care without putting too much strain on broader society, as these solutions do not cost money or bother the health care infrastructure or the personal care givers.

In that connection, this portrayal veils the difficulties of providing for elderly relatives, omitting the pressure that especially women are often under when it comes to committing to the task of giving care for their relatives. Ferrant et al. point out that “[a]round the world, women spend two to ten times more time on unpaid care work than men” pointing to an imbalance not only in elder- but also in childcare. The audience never learns how the daughter copes with bringing her mother lunch every day or what other caregiving duties she fulfills. It is not touched upon where she lives or if she has a job. Instead, she is only portrayed briefly twice, once when she is bringing lunch and once when she is playing cards. Of course, this is a documentary focusing on the life of a centenarian but by leaving out the struc-

tures behind her life, it also denies the caregiving community a voice. Ultimately, this narrative fosters a neoliberal perspective on caretaking, propagating a model that has elderly people staying at home and being taken care of by family members instead of them moving into a care home facility where, in fact, there might be a social infrastructure not only of care takers but also of peers to engage with.

Ultimately, the 'waiting room' of age may be a different one for centenarians than the one for those who have not reached the threshold of 100, yet. A rather bleak reading of this centenarian narrative is then that turning 100 is merely a 'waiting room' upgrade. Consequently, in these terms, the documentary fails at the chance to become a meaningful source on care advice. Especially the way it covers up issues such as loneliness and loss, as well as questions of care in later life, seems highly problematic. However, this is yet another instance where it appears that the film tries to avoid the pitfall of portraying Pellerin-Cormier's life as either a case of successful aging or a narrative of decline. What happens instead is that it denies the caregiver a voice and becomes a story confirming neoliberal demands and stereotypes about care.

### 3.5 Aldéa Pellerin-Cormier and the Normality of Centenarianism

By presenting a tricable break in the perspectives of Aldéa Pellerin-Cormier on the one hand and Daniel Léger on the other, "A Sunday at 105" allows one to analyze the topic of extraordinary 'old' age from two angles. Consequently, the documentary shows that there can never be a strictly black and white image of age(ing) and that individual perspectives influence representations. The cultural imaginary presented here is not as idealistic and sensationalist as that of Helen, discussed in the previous chapter. More often than not the centenarian's age categories seem to more or less align. Yet, the fact that she is a centenarian in the first place lets any representation of outward, behavioral, or physical age seem 'young' in comparison to her institutionalized age. In that connection, the cultural imaginaries presented go along the lines of other media representations of centenarians trying to stage the centenarian as paragon of aging. Generally, there seems to be an ever-present tension between the portrayal of extraordinary 'old' age and the portrayal of 'old' age, clearly showing that, although centenarians are fabricated as a distinct age group, they do share some commonalities with 'old' age.

In terms of social structures, the narrative implicitly engages with questions of isolation. Pellerin-Cormier regards herself as being inactive and isolated most of the time. The images of the documentary, on the other hand, portray her as very much part of the social structure of the family. While she is not portrayed as being disengaged, she seems to feel that way. What is clearly shown here, however, is that



the disengagement Pellerin-Cormier feels is not a result of her actively seeking it. Rather, she appears ready to engage and be part of society.

When it comes to the aging body, and therefore biological implications of age(ing), the centenarian's perspective seems to be more nuanced than general ideologies of progress versus decline. That is, Pellerin-Cormier is aware of the physical age(ing) process and seems content with the limitation that she faces because of it. For her, physical ability does not necessarily appear as a focal point of her everyday life. The narrative surrounding her, on the other hand, suggests differently by portraying her as physically very fit, especially in connection to her institutionalized age, and physically very active.

Ultimately, Pellerin-Cormier herself does not seem to see herself as a role model or an other 'other' in terms of 'old' age. Rather, she appears to regard herself in terms of a continuous life in progress that is not defined by institutionalized age. Léger, on the other hand, focuses on the instances where his great-grandmother can be imagined as a role model of aging, portraying her not in a sensationalist, yet in an extraordinary way. By also portraying what is believed to be her perspective, however, the documentary does become a rather nuanced discussion of extraordinary 'old' age that portrays success, failure, progress, and decline as well as several shades in-between.

## 4 Extraordinary 'Old' Age and (Auto)Biography: George Dawson's *Life is So Good!* at the Intersection of Age(ing), Race, and Class

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The growing interest in accounts of centenarians is not only satisfied through visual media but also through written narratives. Alongside a general boom of written auto/biographies in North America and especially the U.S., there is an emerging genre of centenarian (auto)biographies. Besides many self-published narratives and collections of stories, there have been a few publications by well-known publishing houses that generated the interest of a large number of readers. Among these more prominent narratives, the story of George Dawson gained fame, as Dawson was represented in the media because he learned to read and write at the age of 98. Dawson's (auto)biography is promoted by its publishing house Penguin Books, as a "remarkable book" which tells the story of "a slave's grandson who learned to read at age 98 and lived to the age of 103." He "reflects on his life and shares valuable lessons in living, as well as a fresh, firsthand view of America during the entire sweep of the twentieth century" ("*Life is So Good!*"). This description of the book, taken from the Penguin website, indicates the three main selling points of the narrative: first, Dawson is an African American who grew with the legacy of slavery directly graspable; second, he achieved literacy very late in his life; third, he lived beyond the age of one 100.

Dawson was sought out by Richard Glaubman who convinced him to write down his life's story and thereby to contribute to the fairly new trend of writing centenarian (auto)biographies ("Biography"). The product of the collaboration, *Life is So Good!*, was published in 2000. As opposed to the accounts discussed in the previous chapters, this full length (auto)biography does not merely focus on what it is like to *be* a centenarian, but it also tells the story of *becoming* one. In that sense, the narrative presents itself as a special case within the corpus of texts chosen for this study, as it raises questions of how 'young' age, 'middle' age, and 'old' age are represented from the perspective of a centenarian. It is thus the special concern of this chapter to trace the representations of age(ing) not only in extraordinary 'old' age but also throughout Dawson's entire life-course.

Furthermore, the fact that this is a co-authored narrative gives questions of autonomy a different nuance than the videos discussed in the previous chapters. Whereas in Macklemore's music video, it is perfectly clear that the audience gets to see a staged setting and therefore a 'real' centenarian acting out the story of her own one 100<sup>th</sup> birthday, Aldéa Pellerin-Cormier's representation leaves open the question of scripting, yet, she gets to respond to questions and thereby performs a certain autonomy. George Dawson and his co-authored (auto)biography present an opaquer situation of agency, as the reader can never know whether they read the voice of Dawson or the voice of his co-author Glaubman. Therefore, the modes of production and the question of agency will be prominently addressed in the first part of this chapter.

The second part of the chapter deals with the topic of aging through the life-course. I elaborate on African American aging and investigate how Dawson's blackness influences his life-course in general and his aging process in particular. As the narrative follows Dawson through his life in the Jim Crow South, his travels throughout the U.S., Mexico, and Canada, and his encounters with racism and discrimination, it suggests itself to read the book from an African American studies perspective. This chapter thus not only presents a change in medium but also faces the challenge of discussing age in light of blackness and masculinity, rather than whiteness and femininity. Consequently, this chapter specifically deals with the challenges of black aging and what it means for the representation of centenarians on the one hand, and the construction of centenarianness on the other. Furthermore, I look at the way Dawson is 'aged by culture' not only in terms of his race but also through class, education, gender, and his everyday surroundings.

The third part of this chapter specifically discusses how Dawson's centenarianness is portrayed and constructed within the narrative. Bearing all the previously mentioned aspects in mind, the last part of the chapter returns to the construction of Dawson's extraordinary age in at the intersection of the cultural, social, and biological.

Dawson's portrayal leads to an illusion of social mobility, claiming that no matter the odds, with hard work and persistence, anybody can achieve anything. By promoting Dawson's mobility, in a physical, as well as a social sense, in his extraordinary 'old' age, the narrative suggests that, once a person has reached the status of being a centenarian, race related issues become secondary. I aim at reading blackness and age alongside each other to understand how one influences the other. In this connection, it is crucial not only how different age categories gain relevance in different situations but also in what situation age(ing) or race are important markers of difference. How does the fact that Dawson is black influence the perception of his aging process and, on the other hand, how does his status of being a centenarian influence the perception of him a black person? Ultimately, the discussion of George Dawson goes to show that, in terms of extraordinary 'old' age, he is

fabricated with the distinct markers of centenarianness, showing that this newly emerging age group is imagined in a generalized way, glossing over cultural, social, and most importantly, racial differences. The fabrication of centenarians can thus be accused of engaging in a discourse of color-blindness.

#### 4.1 Co-Authorship, Vulnerability, and the Art of Age (Auto)biographies

Whereas the material discussed in the previous chapters focuses mainly on being a centenarian, *Life is So Good!* as the full length (auto)biography of George Dawson describes scenes from various stages of his life in detail. Therefore, it is not, as Katherine Woodward criticizes many accounts of 'old' age to be, merely "words, plucked as they are to fit the compact and condensed frame of a news story, [that] necessarily lack the sense of a vital connection to a unique life" ("Telling Time" 65). Woodward is concerned that a narrative solely about 'old' age denies the aged person a history and therefore a personality that is not primarily defined by being 'old.' Hence, Dawson's life narrative works against this impression, setting extraordinary 'old' age apart from 'old' age yet again. Dawson, as a centenarian, is granted a history and gets to tell his life story because of his extraordinary 'old' age. However, Dawson's (auto)biography does not completely satisfy Woodward's requirements for the 'perfect' age narrative. She "long[s] for the contours of individual voices reflecting on their own experience and speaking, as it seems, directly to [her], not words mediated by a website content provider or an interviewer" ("Telling Time" 66). Since the narrative is a co-production of Dawson himself and Caucasian primary school teacher Richard Glaubman, it is impossible to untangle whose voice is heard within the story. Therefore, the narrative at hand is a mediated one, as Dawson told it to Glaubman and Glaubman wrote it down. The extent to which this influences the result of this collaboration is not clearly distinguishable. Nonetheless, looking at the modes of production of *Life is So Good!*, is fruitful in terms of voice, agency, and the power of narration.

When it comes to the question of agency, *Life is So Good!* serves as an interesting example for two reasons: first, unlike the two video examples discussed in the previous chapters, Dawson's narrative is surrounded by a number of para-texts. Accounts on websites, publisher's notes, or acknowledgements provide at least some insight into the modes of production of the story, and therefore a better understanding of the politics of agency. Second, the co-author of the narrative is part of the story and thus the relationship between Dawson and Glaubman becomes a subject matter of the book and can be analyzed.

From the publisher's homepage, the reader learns that Glaubman interviewed Dawson and then supposedly did a great job in "captur[ing] Dawson's irresistible voice and view of the world, offering insights into humanity, history, hardships,

and happiness" ("Life is So Good"). The publishers suggest that Glaubman did the writing, yet, he imitated Dawson's voice in a way that it seems plausible enough that it appears as if Dawson is speaking to the reader. In other words, Dawson told his life story and Glaubman translated it into a sellable narrative, leaving the reader not with the voice of the centenarian but with the co-author's interpretation of it. Glaubman thus becomes a mediator between Dawson and the public and, at the same time, a "vulnerable subject" as described by Couser in the sense that due to his age and rudimentary literary skills he is "vulnerable to misrepresentation" (x) by his co-author. In the case of *Life is So Good!* Dawson's vulnerability increases because of general power structures of U.S. society. It remains questionable whether a middle-aged man is truly capable to capture the voice of someone who has grown up in an entirely different space and time. Additionally, and maybe even more crucial, it is highly problematic for a Caucasian man to speak for an African American.<sup>1</sup>

Suspicious about Glaubman's take on the ethics of life writing arise in the acknowledgements of the (auto)biography. Not only does Glaubman repeatedly refer to the book as "my work," he also writes: "I humbly offer this book as a tribute to George Dawson for the life he has lived" (ix). Hence, even though he "humbly offers" what he has written about another person's life as a tribute, it becomes clear that Glaubman sees himself as the dominant and more important agent in this collaboration. Further, he may also be the main profiteer of the collaboration, as Dawson signs the rights to the book to Glaubman which is described as a triumph within the narrative. Dawson, in this scene, is able to actually sign his name on a contract for the first time in his life. Dawson did not take the decision to sign lightly. He explains: "I had to think on [signing the contract] some more. Nobody said nothing. I knew I was with friends and whatever I chose would be okay. . . . It was quiet for a long time. It was for me to decide. I put my glasses on and signed in cursive" (256). The narrative here suggests that Dawson's decision to have his

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1 Here, the relationship between Dawson and Glaubman begs for an analysis through the lens of slave narratives. As the common slave narrative, *Life is So Good!* tells the story of an African American who achieves a major change in life. For the slave narrative, this was the transition from bondage into freedom. Many narratives work with the common framing that 'education is key' to a life as a free person (Coleman). This mantra is taken up in Dawson's life story, as it presents his achievement to learn to read and write as the greatest achievement of his entire life. Furthermore, slave narratives work with a white abolitionist's foreword, validating the written account to a white audience (Coleman). The same mechanism can be seen in *Life is So Good!*. In that connection, it is also notable that many (auto)biographies of African American centenarians (cf. Delany, Delany, and Hill Hearsh; Cheeks Johnson and Mulcahy) have Caucasian co-authors. This new genre of African American centenarian (auto)biographies, thus demands a reading as a continuation of the traditional slave narrative, an academic endeavor which goes beyond the scope of this study.

(auto)biography published is an autonomous one. Yet, he presumably did not benefit from it, as the rights and profits largely remain with Glaubman and continue to do so after Dawson's death. Glaubman still gives talks about his experience of writing *Life is So Good!* ("Appearances") and has published a second narrative about George Dawson after his death (Glaubman). Consequently, it is crucial to keep the relationship between Dawson and Glaubman in mind and to be aware that this might, yet again, not be an account of the centenarian's voice but rather a staged story where Glaubman acts as the ventriloquist and Dawson as the puppet.

In addition to the dominance in the claim on the rights to the book, Glaubman has also been accused of dominating the narrative itself. In the online blog *Pratie Place* the author criticizes that "Dawson's Ghostwriter, Richard Glaubman, is annoying. Far from being a Ghost, Glaubman is overweening from the very first sentence" ("George Dawson Update"). According to this blog, Glaubman is present throughout the entire story through the style of writing. In the post, the author claims that it would be very unlikely that Dawson, as a person who is not formally educated and had just started to learn to write, would begin his life story with the grammatical construction of a gerund. While this statement itself can be accused of being highly classist, it nonetheless raises suspicions about the voice the reader gets to hear. These suspicions are intensified throughout the book, as the style of writing switches between General American English in the overall narration and African American Vernacular in Dawson's speech acts. As Lejeune describes in his theory of the "autobiographical pact," both, narrator and protagonist, need to be the same person in order for a work to be considered an autobiography. The break in writing style in *Life is So Good!* indicates otherwise.

Besides these indications deriving from the texts surrounding the narrative, Glaubman is also featured as a character within the book. His appearances, which are usually situated at the beginning or the end of a chapter, frame Dawson's life narrative and tell the story of how the book was written. Glaubman is introduced to the readers through the narrator George Dawson as follows:

His name is Richard. He has lots of questions, thinks he wants to write a book. He comes with a tape recorder and we just sit and talk all day. He's different than other people that I know. I don't mean because he's white or because he's younger than me. Most folks that I know don't read as much and don't have great book learning. This man Richard is different that way. He's read a lot of books and knows about things I never heard of. (41)

This introduction offers insight into the writing process of the (auto)biography. Glaubman had interviewed Dawson and then wrote he the book. This knowledge makes the passage all the more ironic. After all, it was written by Glaubman imitating Dawson's voice who probably spoke to his co-author about the way he felt being interviewed. This irony or entanglement of different voices is approached

by Gabriele Linke who argues that the “process of transforming oral histories can be characterized as the collective (re-)construction of meaning. . . . In this way, oral historians and their interviewees jointly create the autobiographical narratives. Here, personal recollections are mediated for the first time” (76). According to Linke, Glaubman and Dawson both function as mediators of Dawson’s story. The narrative is based on a joint process of conducting interviews that is then translated into a coherent book and thus mediated for a broader audience. With this mediating process, it is not only important to create a narrative that makes sense to a large variety of readers but also to establish the illusion that it was told by Dawson himself entirely and that *Life is So Good!* is an ‘authentic’ ‘as-told-to narrative.’

‘As-told-to-narratives’ were especially popular in a Native American context. Edward Valandra elaborates that “a significant portion of the ‘as-told-to’ formula involves a non-Native writer who brings all of his or her cultural and racist baggage” (109). He criticizes narratives that involve writers who come from an entirely different cultural background than the person they are collaborating with. This same mechanism can be found in the production of *Life is so Good!*, not only in terms of race but also in terms of age, class, and education. It is then crucial to understand that the narrative is not merely the story of a centenarian but that this is an account that has been mediated through a number of voices and is, although it might advocate a certain ‘authenticity,’ to be treated as another performance of not only centenarianism but also blackness through the lens of middle-aged whiteness.

## 4.2 Aging through the Life-Course: The Interconnectedness of Race, Class, and Age

With the complex relationship between the producers of the narrative in mind, this subchapter focuses on the way George Dawson is ‘aged by culture’ as well as by the social structures that influence and are influenced by cultural imaginaries. Despite the increasing number of published life narratives and the scholarship surrounding them, aging studies scholars criticize the absence of critical engagement with the aging process within the genre. Gullette, for instance, points out that “autobiography, and life storytelling as a whole, could become far more acutely aware of the ways in which people are aged by culture” (“From Life Story Telling” 103). In this statement, Gullette connects her claim of people being ‘aged by culture’ to the genre of life narrative. She asks for accounts that are aware of age being not merely a chronological or biological fact but a cultural construct. I would add that not only the way culture deals with age(ing) and its representations, but also social hierarchies add to the way people are aged. While George Dawson’s narrative might not be one of these age aware narratives Gullette imagines, his story often reveals the ways in which cultural forces and social expectations influence his aging process.

In that connection, there is a special focus on the way age(ing) and race interact as categories of difference throughout Dawson's life. Therefore, I will first focus on the way racial issues influence his life-course and therefore his aging process. In a second step, I will give examples of how age is constructed under the influence of other factors, not primarily concerned with race.

As Dawson travels through the U.S. and encounters his own difference in various spaces, the book promotes an image of possibility that is very much like a narrative of the American Dream in the sense of a "self-made man." Although often connected to Benjamin Franklin and his autobiography (Paul 370-371), the concept was also used and adapted as a more inclusive concept by Frederic Douglass in a lecture of the same title:

Self-made men are the men who, under peculiar difficulties and without the ordinary helps of favoring circumstances, have attained knowledge, usefulness, power and position and have learned from themselves the best uses to which life can be put in this world, and in the exercises of these uses to build up worthy character. . . . Such men as these, . . . whether Caucasian or Indian; whether Anglo-Saxon or Anglo-African, are self-made men and are entitled to a certain measure of respect for their success and for proving to the world the grandest possibilities of human nature, of whatever variety of race or color.

Douglass clarifies that all men, no matter their race, can become self-made men, if they come from nothing and work hard to achieve something. This sentiment is presented in George Dawson's (auto)biography, as well. Much like Benjamin Franklin's autobiography, which suggests a set of rules for healthy and moral living (97-80), Dawson's narrative provides a manual on how to lead a good life and become the best possible self. Thereby, it not only connects a story that is, due to the fact that it is told by a centenarian, about age, to a story about racial discrimination, it also uses the trope of social and spatial mobility in order to cover up barriers U.S. society puts up for people of color, poor people, or people of certain age groups.

#### 4.2.1 African American Aging

*Life is So Good!* assigns great value to both the categories of age and race from the very beginning. In many instances, the two aspects are intertwined or related. This relation between age(ing) and race is also pointed to by Frances Adomako in a fact sheet on African American aging, provided by the American Psychological society. Adomako describes that "African American older adults experience significant health disparities, including lower life expectancies and an increased risk of chronic health conditions such as hypertension, diabetes, dementia, stroke, and cancer" and that these higher risks of disease may occur due to "race-related stress," that



is, “[racist] encounters [which] are accumulated over the lifespan, stored in memory, and relived with each new racist and discriminatory experience.” If encounters of racism put stress on the body, which is then stored and remembered, the bodies of older African Americans are under constant pressure. The aging process itself, especially when it comes to physical age, is thus affected by the outside world. At the same time, as Adomako points out, ‘old’ African Americans have “[l]imited access to community resources (e.g., grocery stores, pharmacies, culturally competent health and aging service providers, transportation, housing, etc.)” and therefore lack essential resources to lead a good and meaningful life in later years. *Life is So Good!* implicitly discusses the interplay of race and age, however, it disregards the far-reaching effects racism may have on the aging process as a whole. By playing down racist encounters in the first place and staging Dawson as a model centenarian without referring to the problems of black aging in the United States, the story rather denies the realities of the influences of racial tensions on an individual’s life. At the same time, it discusses how both age and race are constructed and reconstructed alongside each other throughout Dawson’s life-course.

The first time Dawson is confronted with the fact that age has meaning is when he is eight years old and realizes that the children surrounding him are entering school. He states that “the last of the Coal children [white children, Dawson used to play with], was to be starting school in the fall, I was eight years old and that’s about when children started being just with their own color. Besides, I was getting too old to play anyway. That spring, I started working full-time” (29). In this instance, he not only realizes that age can mean something, it also becomes apparent that this meaning differs from context to context. That is, only if a family can afford to manage without the workforce, a child’s turning a certain age means the start of school. The narrative shows how people are indeed ‘aged by culture’ and underlines that these cultures can be very different in a very limited space. The way institutionalized age influences the life-course thus depends on the cultural and social background, as well as the historical time, a person lives in. Simultaneously, Dawson gains a stronger awareness of race. Eight is the institutionalized age at which children who can afford to do so start school. Additionally, it is the age where the color line becomes solid. Whereas playing with white children is not a problem for Dawson before he turns eight, afterwards it becomes unthinkable because of ever-present social boundaries. In that sense, the narrative shows how the perception of race is highly influenced by a person’s age.

These racial lines are made even more impermeable as Dawson goes to work on a farm at the age of twelve. Instead of being in school, he is now ‘old’ enough to work for a white family away from home. Although working away from home would generally be considered a ‘grown-up’ task, Dawson’s grappling with the situation indicates that he does not yet fit the role of an ‘adult.’ He gets homesick and “that first night, even under the blanket [he] shivered and [he] cried till [he] fell

asleep" (54). Although the circumstances demand for him to behave like a 'grown-up,' his unusual life-course cannot hide that he is still a child. In that sense, his institutionalized age forces him into a behavioral age that he may not be ready for, in turn forcing him to 'grow-up' faster in order to cope with his circumstances. Ultimately, the reason for the necessity of his premature adulthood certainly lies in his race and class. Because his family is African American, living in Texas in the early nineteen-hundreds, they do not have very limited opportunities to make enough money to provide for their family without the labor force of their oldest son. Therefore, age, race, and class are inextricably linked.

Through his race, Dawson is required to act unusual for his age. The parting advice he gets from his father, not to mingle with white people, is regarded by Dawson as "part of growing up" (49); a ritual that occurs at the threshold between childhood and adulthood. This special ritual emphasizes the importance of race over the importance of age. Dawson gets behavioral advice not only because he is technically still a child and would be considered to behave as such, but because he is black. His status as an almost 'grown-up' who is earning money to support his family does not help him on his path to become an independent individual. Rather than his age, at this point, it is his race that defines his life.<sup>2</sup>

After Dawson spent his childhood working in order to help supporting his family, his father allows him to keep his wages once he turns 21. This presents to be step toward adulthood and responsibility in terms of financial freedom, marked by institutionalized age. Dawson uses this newly gained financial independence to start traveling. In this instance, his institutionalized age defines the spatial freedom, he is granted. Before turning 21, he was not able to travel, because his father made economic and life-altering decisions for the entire family, including Dawson. Now that Dawson is an adult in terms of his institutionalized age, his father grants him to manage his own finances. This responsibility, in the eyes of the father is not connected to Dawson's behavior or the question of whether he is capable to handle it but to the mere occurrence of a birthday. Dawson's father thus measures age solely by its institutionalized component.

Besides making claims about the aging process, Dawson's ability to travel implies a certain economic well-being. Furthermore, him travelling through the Jim Crow South as an African American, suggests that it was indeed possible for African Americans to travel rather effortlessly. However, his encounters on the road show

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2 While working for a Caucasian family, not only racial matters that are connected to Dawson's age are foregrounded by the narrative. Dawson has to enter through the backdoor, is not allowed to sit at the same table as his employers, and ponders the question how he, as an African American boy, is allowed to behave in an all-white environment (54-55). All these aspects are certainly worth discussing, yet, a detailed analysis of the narrative in terms of critical race theory goes beyond the scope of this study.

that he can never escape the stigma attached to his skin color. He explains that “[i]t wasn’t easy for a colored person back then to travel. Matter of fact, it could be dangerous. Sometimes, other coloreds would step in and warn a traveler” (111). Thus, spatial mobility can only do so much. Dawson is, wherever he goes, an outsider who is unable to permeate social walls. However, the book highlights situations in which he is more accepted, suggesting that he is content with his social boundaries, as long as he can move freely in the sense of spatial movement. Although the narrative does not deny the dangers of traveling for an African American completely, it promises that with the right behavior things should remain uncomplicated. The necessity of a ‘right’ behavior is reinforced a few years after Dawson has traveled the South by the publication of *The Negro Motorist Greenbooks* (Green). These books were designed for African American road trippers and advised them on dangers and possibilities while traveling. Yet, Dawson’s narrative manages to mostly disregard the fatal dangers whose existence the emergence of the *Greenbooks* show. In other words: before the *Greenbooks* assisted African American travelers by telling them where to go and—more importantly—where *not* to go, traveling while black was not only dangerous but, in many cases, life-threatening.

Although the life-threatening nature of traveling while black in the Jim Crow South is mostly disregarded, *Life is So Good!* hints at minor occurrences of racism. For this study, especially those moments are of interest where age and race are mentioned in the same instance. This happens, for example, when a ticket agent at the train station asks Dawson, who, by that time, is in his twenties: “Where are you going, boy? I was a man, but that didn’t matter to him” (131). Here, age and race are intertwined linguistically. Whereas the word ‘boy’ is a marker of ‘young’ age and childhood, it is also used as racial marker, as white people used to refer to black people as ‘boy.’ Consequently, ‘blackness’ and ‘childhood’ are linked together, taking away adult agency from African Americans. In that connection, Corinne T. Field argues that historically, citizenship and therefore social and political participation was tied to adulthood, which was denied to women and African Americans because their maturity was questioned by a white, male norm (3). There was thus no “equal adulthood” (1) which becomes visible through the use of the word ‘boy’ to address a grown man. In this instance, bringing age and race together on the one hand results in racism, as Dawson is denied being treated as an adult and is denied being a full member of society which then results in a lack of empowerment. On the other hand, this derogatory treatment of African Americans only functions in a mindset where children do not have agency. As African Americans and children are put on the same level, it becomes clear that both groups are not expected to be able to take care of themselves and are denied agency.

After his life as a traveler, Dawson settles down, gets married and has seven children, all in accordance with the expected life-course of a man. It is only after his official retirement when he is working for a white woman as a gardener that the

narrative hints at the interconnectedness of age and race again. In this encounter ageism and racism mutually influence each other. When Dawson works on hot day his employer states: "I guess that heat doesn't bother you people. You're fortunate that you can just keep working. It's so hard for us, especially when we get older.' Now, I was sixty-five and at least as old as she was" (209). First of all, there is a clear 'us vs. them' distinction and the expectation that black people are generally not influenced by weather conditions in the same way as white people. This racist assertion is presented as something positive, whereas the woman ignores that Dawson working in the heat is not because he *can* but because he *must* for economic reasons. This basic claim is then supplemented by the assumption that African Americans age differently than Caucasian Americans. Either the woman categorizes Dawson in the wrong age group due to his physical abilities and outward appearance; or she thinks that age means something different for her than it does for him. The generalization shows that the woman regards Dawson as fundamentally different from herself because of his skin color. In the eyes of a white woman in her sixties, Dawson's age thus does not matter at all. The only necessary category of difference remains race.

Even though Dawson encounters these forms of racism, at the point in history where African Americans throughout the country begin to collectively fight for civil rights, he does not join the protests: "I wasn't one that marched on Washington or joined the marches across the South. It just wasn't me. I was an old man by then and it wasn't the way I been living all those years" (213). This statement, in line with the rest of the narrative, promotes a certain contentment with his situation. Dawson managed to have a decent life without equal rights and apparently never thought about striving for more. By distancing himself from the civil rights movement, Dawson engages in so called 'respectability politics.' Mikaela Pitcan et al. describe respectability politics as

rooted in resistance to racist imagery of Black people, particularly Black women, who adopted self-presentation strategies that downplayed sexuality and emphasized morality and dignity to reject White America's stereotypes of them. In this context, respectability is a tactic used by low-status individuals in the hope of obtaining social mobility.

As a black male, Dawson resists stereotyping by working hard and not criticizing white dominance. In that sense, he is depicted as harmless towards a white, male, and heteronormatively dominated society. Moreover, Dawson's attitude toward the civil rights movement shows how now, in his later life, it is his age, or rather the behavioral expectations he sets for himself in relation to his age, that prevents him from pursuing equality. Ironically, whereas in his earlier life it was his age that gave him freedom as he could escape the race restrictions of the South, in his sixties,

age seems to be the restrictive factor. As he had lived with discrimination his entire life, at his age he seems ready to continue do so.

The connection between age and race continues to be an important factor in Dawson's life, especially once he turns 100. Primarily, the relationship to his co-author is not only questionable because Glaubman is so much younger but also because he is white, facts that, in the social power dynamics of the U.S., give Glaubman more agency than Dawson. Further, in this case the question suggests itself whether this narrative is so successful because Dawson was "a slave's grandson," because he "learned to read at age 98," or because "lived to the age of 103" ("Life is So Good"), inextricably linking issues of age, education, and race. Since Glaubman only sought Dawson out *after* his one 100<sup>th</sup> birthday, age appears to be the defining factor for the production of this (auto)biography. However, it is noteworthy that among the many centenarian (auto)biographies flooding the market in recent years, those which have been most acclaimed and published with renowned publishing houses are those about African American centenarians (cf. Delany, Delany, and Hill Hearth; Cheeks Johnson and Mulcahy). While, as I will argue in the following sections of this chapter, there are certainly instances where Dawson is aged by cultural forces that are not primarily linked to his race, there appears to be a connection between age and race when it comes to the production and perception of centenarian (auto)biographies. The fascination of an exceptionally long life seems to be reinforced through narratives about people who did *not* have the perfect conditions getting there in the first place. The narrative of the American Dream of aging works even better if the goal is achieved against all odds. At the same time, this line of reasoning brings back neoliberal ideas: if people who had to face discrimination and poverty throughout their lives can healthily and happily live to 100, more privileged people have no excuse of not doing the same.

Ultimately, this section showed the extent to which categories of difference, in this case primarily race and age, mutually influence each other. When they occur together, especially in Dawson's early life, race seems to be more of a defining category. Later on, especially when it comes to his lack of participation in the civil rights movement, his age, too, becomes a restricting factor. The narrative also shows that Dawson's cultural aging is very much influenced by his race. His life-course, and therefore the meaning of different life stages is affected greatly by his social standing and the fact that he is black. Clearly, his aging process is not solely defined by his race. Sometimes race and class are inextricably linked and sometimes other factors influence Dawson's aging process. The next part of this chapter thus focuses on the way Dawson ages through the life-course in instances where race is not the defining factor of the process. As his race is implicitly ever-present, however, it can never be completely muted within the analysis.

### 4.2.2 Aging Through the Life-Course

This section focuses on the instances in Dawson's life where the construction of his age is not primarily influenced by his race. I am discussing examples where age becomes the defining moment of his life as well as those where his aging process is influenced by the culture, he lives in.

During World War I, Dawson works at a sawmill whose owner values his work enough to forge his documents in order to make him appear younger than nineteen and therefore not fit for war. He states: "I was about nineteen years old. I didn't know much about the war. But from the way people talked, I thought I might be going too. The mill owner changed my birthday on a piece of paper" (88). This action shows the extent to which institutionalized age influences a person's life. Since the military has inscribed the rule that only people over the age of nineteen can be drafted for war, every person who has not reached that threshold is free to stay at home. Furthermore, it shows how just 100 years ago, the system of institutionalized age was easy to evade, especially for a person who was not part of mainstream society. Yet, it shows that age is a category one can, at least to some extent, lie about, as long as the different age categories still somewhat align, that is, because Dawson's behavioral, outward, and physical age do not oppose the altered institutionalized age. What this section shows, then, is that a certain age brings opportunities and responsibilities. In that connection, being a certain institutionalized age at a certain point in history may drastically change a person's life-course and thus bears immense power.

Dawson uses the freedom of not having to go to war and being released from the duties of financially supporting his family to start traveling at the age of 21. While his spatial mobility thus increases during his twenties, his social status remains the same, due to his skin color and the lack of education. Yet, his attitude towards life, and his motivation to always work hard at least provide the economic means for him to travel. He is a low budget traveler and the fact that his travels are interrupted by periods of working reminds the reader of the fairly new trend of 'Work and Travel,' the possibility for mostly Western 'young' adults to live, work, and travel within a foreign country for a year. In that sense, the travel narrative reads like a coming-of-age story. Although the narrative does not present strictly "crises of late adolescence involving courtship, sexual initiation, separation from parents, and choice of vocation or spouse" ("Coming of Age"), it deals with the instances in which Dawson learns how to cope with life on his own. As well as many 'young' adults nowadays travel after high school in order to gain independence, Dawson describes many instances of growing up or becoming an adult throughout his journey.

When he takes his first job building levees along the Mississippi River, for example, he states that "I was excited about 'my wagon' and 'my mule' as if I was just a kid

and not a man of twenty-one years of age. I may have been grinning like a kid, but I felt like a man, all right" (119). Dawson hence describes himself in an in-between state of child-and adulthood. This is the first time in his life that he has a job that he acquired himself and that only he will benefit from. Further, it is the first time in his life that he is in charge of property. Even though he just rents the wagon and the mule from his employer, he is responsible for them and for the time being, they are his. Adulthood is thus tied to two different things in Dawson's narrative. First, to the number of 21, a number that is institutionalized as a milestone of growing up in the U.S. until today. Moreover, Dawson 'feels like a man' because of his responsibilities. Conversely, he admits that he might have acted like a child, presenting a juxtaposition of outer and inner perceptions of age(ing): what a person feels—in Dawson's case the feeling of being an adult—does not necessarily align with what other people see—in Dawson's case, a person who is excited like a child.

Interestingly, this passage also introduces questions about perspectives on the life-course. Being 21, riding on 'his' wagon, Dawson feels like an adult; looking back on the scene and narrating it from his perspective of a centenarian, he questions his own feelings of maturity. It is also clear that from whichever perspective this tale is told, behaviors such as excitement and grinning are regarded to belong to children, whereas—following that logic—adults must be sincere and calm. It seems that perspectives on what attributes belong to a certain age group change with the age of the onlooker. Whereas 21-year-old George Dawson feels like an adult due to his responsibilities, his centenarian self takes into account other behaviors and considers himself at 21 to be rather childish. This emphasizes the arbitrariness of age as a cultural construct as intrinsic or extrinsic identification is constantly renegotiated through human interaction.

The travel narrative of the book is restricted to Dawson's younger years and, as he grows older, he marries and settles down back in the South. At this point, Dawson returns to a rather normative model of the life-course, indicating that there is a certain time and place in life to settle down and start a family. Here, again, age is the decisive factor in his decision. Hence, his age becomes the restrictive factor to his spatial mobility. Because he is ready to have a family at the age of 28, he has to stay in one place. The woman he meets and falls in love with is twelve years younger than Dawson, which points toward constructed ideals of age differences in a relationship. Generally, the preferred age in a partner for males is significantly lower than for a female, that is, in a heteronormative relationship, the male partner presumably needs to be older than the female partner (DiDonato). It is thus socially acceptable for Dawson to marry a woman who is twelve years younger than himself, while the other way around would not be as easily acceptable. Here, the narrative hints at the distinct difference between male and female aging, thereby pointing to Susan Sontag's 'double standard of aging.'

In that connection, it is also noteworthy that Dawson, after his first wife passes away, gets remarried three times, a significant fact, as social mechanisms of age(ing) do not restrict elderly males from romantic relationships, as much as females.<sup>3</sup> Once he is 100, he even states that “[p]eople always ask me if I will ever get married again. I might. I might. There’s lots of women that would like to marry me” (219). As opposed to Aldéa Pellerin-Cormier, who cannot imagine having a relationship at her age, Dawson would happily get remarried. He claims that there are many women who would be interested in marrying him. Apparently, he is still very much desirable and therefore an eligible bachelor. As men age differently than women, romance in ‘old’ age seems to be more likely to occur. Here, a comparison between the narratives of the female centenarians previously discussed with the one of George Dawson intensifies the notion of a ‘double standard of aging’ and emphasizes that gender norms are still very much significant into extraordinary ‘old’ age.<sup>4</sup>

When Dawson reaches retirement age, social security is not enough for him to get by and he continues working as a gardener until the age of 89. He only retires because his tools are stolen and he cannot afford new ones (221). When he retires from his official job, he explains: “[w]hen I had to quit my job in 1963, I didn’t stop working. Even if I wanted to, I couldn’t have done that” (208). Due to economic reasons, Dawson’s work life is tremendously extended. He had to ‘grow up’ early in order to support his family and keep on working far longer than would be considered the social norm. If ‘old’ age is connected to a lack of economic productivity and retirement, Dawson’s midlife is considerably stretched. John Macnicol explains that “there has been increasing pressure to redefine old age almost out of existence in the name of agelessness, to remove the protective walls that have hitherto shielded older people and, in the process, to attack their welfare rights” (2). As Dawson does not retire—because he is financially unable to—he is, in a way, staged as ageless.

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- 3 Age here does not seem to be a factor that matters too much when it comes to choosing a partner. Race on the other hand is given a very high importance, as Dawson does not even allow himself to speak with a white woman—which, given the realities of the Jim Crow South, appears to be a safe course of action. Furthermore, education appears to be a deceive factor for Dawson, as he cannot ask a woman, he meets on the train out because he thinks that her literacy makes her too different (147). Categories of difference thus gain and lose importance due to the situation Dawson finds himself in.
  - 4 Another issue pointing toward gender difference in extraordinary ‘old’ age would be that in the narratives about Helen and Aldéa Pellerin-Cormier, outward appearance was a major topic while it is mostly left out in Dawson’s case. This, of course, may not only be because of gender differences but also because the previous two narratives were told within visual media, allowing for more of an emphasis on outward appearance. Yet, there is no mention at all of Dawson’s appearance at 100 throughout the entire book, indicating that his appearance just is not important for his persona.



This then ties into a neoliberal discourse of the necessity of protection of 'old' people and the need for welfare. If, in other words, everybody aged as 'well' as George Dawson, there would be no vulnerability among the elderly and thus no need for protection through the community. Dawson's narrative shows that working beyond the average U.S. retirement age of 65 is possible but, at the same time, implicitly criticizes the lack of protection he is given. Ultimately, his continued employment shows that class is a significant factor in the structure of a life-course. Money, in Dawson's life, is the determining factor on when he has to 'grow-up' or when he can 'grow old.'

The unusual structure of Dawson's life-course continues as he goes back to school at the age of 98. Interestingly, Dawson himself states that the imaginary of a model life-course kept him from doing so earlier: "People wonder why I didn't go back to school earlier. After I retired, I finally had time. I was proud to get my children through school and raise them properly. But I understood that school was there for children" (226). The conventions of the life-course restrict Dawson from getting an education once he is an adult. Even with fairly new concepts of the necessity of lifelong learning, Dawson's late education does not fit the expected Western life-course model, for as Manuel London writes in his introductory text to the topic of lifelong learning, "[l]ifelong learning builds on prior learning as it expands knowledge and skills in depth and breadth" (3). If lifelong learning is only defined as the continuation of institutionalized learning, Dawson's efforts cannot be defined within this framework.<sup>5</sup> Instead of being an example of the lifelong learning paradigm, he is, yet again, an extraordinary case of starting institutionalized learning in 'old' age. Consequently, the narrative presents an interesting blurring of age categories and life-course models. The fact that the term 'adult education' needs the specification of 'adult' shows that it is something outside the norm, as the term 'education' would be associated with learning in childhood, adolescence, and early adulthood. Hence, by going back to school to learn to read, Dawson enters the role of a child.

Whereas in Western imagination the teacher is usually older than the student, in this case the student exceeds the teacher in age by many years. This role reversal of life stages continues into Dawson's private life where he now comes home to his son to tell him about his day at school, a routine that they enacted with opposite roles when his son was still in school (230). An unusual life-course, which might be inviting stigmatization for some people does the opposite for Dawson as he receives praise and fame. It could thus be argued that the admiration one gets when living an extraordinarily long life increases when coupled with behavior that

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5 Furthermore, lifelong learning, as defined by London, is a process that should be supported through a person's employer (3). Consequently, according to this definition, people who have retired would not be in need of lifelong learning any longer.

is not considered the norm of 'old' age. The phenomenon of being a centenarian is thus amplified by Dawson's going back to school.

His efforts are met with great appreciation that wins him an appearance on the Oprah Winfrey Show where he is promoted as the 'posterchild' for U.S. American literacy. This terminology again promotes the juxtaposition of age and role, as well as reinforcing the irony of it. Because he is going back to school, the centenarian can be referred to as a 'child.' Hence, Dawson's late education could be read as a sign that 'old' age, indeed, is like a 'second childhood.' However, as Achenbaum elaborates, the concept of the 'second childhood' is tied to an idea of cognitive and physical inability and the idea that children cannot take care of themselves ("Delineating Old Age" 301). Consequently, Dawson's illiteracy and the resulting helplessness in a society where literacy is the norm puts him into the position of dependence associated with the 'second childhood.' In his case, however this dependence occurred throughout all life stages and is not connected to the common decline narrative of 'old' age. Rather, Dawson turns this expected decline around by emphasizing his cognitive abilities by going back to school. Interestingly, although he is called a 'posterchild' and openly ponders on the role reversal with his son, he would not be defined as a member of the 'second childhood.' This then shows how arbitrarily these terminologies and the concepts of 'childhood' or 'old age' are in the first place. They mean different things to different people and, most importantly, are connoted in various ways. However, childhood and the dependence that comes with it is not associated with something negative. 'Second childhood,' on the other hand, is regarded as negative. Dawson, by going back to school, establishing cognitive ability, and therefore reinterpreting his late life, reimagines the 'second childhood' as something positive.

Dawson's efforts are not only notable when it comes to renegotiating life-course models, his image as 'posterchild' is supported by his teacher, Carl Henry, as he describes the allure Dawson presents for his adult education program. As Henry states on the Oprah Winfrey Show, his students are impressed and motivated by Dawson's performance. He explains that "[i]f Mr. Dawson can do this, honey, you can do it too" (01:39-01:41). This motivation does not only capture Dawson's classmates but also his teacher, who came back to adult education after his retirement "since Mr. Dawson's been here I don't feel so old. Retirement was good for a few months, but I don't need it" (227). By encouraging Henry to keep working after his retirement, Dawson implicitly passes on the neoliberal values that are prominent throughout the entire narrative. His life thus becomes not only an example of neoliberal values put to action but also starts a chain reaction of people living up to his standards. Dawson, in other words, gives people a purpose. He becomes sort of a prophet so people can now ask 'what would Dawson do?' This role model function does not only work through his strive for education but by his age, as well. When Dawson is around, Henry feels younger himself. With all positive imaginar-

ies connected to being 'young,' Henry's motivation may hence be increased through a feeling of opportunity and progress.

In summary, a critical reading of Dawson's aging through the life-course raises three major issues. First, the fact that we are 'aged by culture' does not mean that 'alternative' life-course models lead to social exclusion. Rather, Dawson's non-normative life-course leads to respect and admiration. At the same time, the narrative shows that there is no escape from the cultural forces of aging, the norms that surround him significantly shape Dawson's persona through his age. Second, the narrative shows that being 'aged by culture' is inextricably linked to social categories of difference such as race, class, and gender. The reciprocal influence of these categories suggest that African Americans are 'aged by culture' differently than Caucasian Americans, women differently than men, the rich differently than the poor. Third, the emphasis on Dawson's work until 'old' age and his efforts to take care of himself and continue learning echo the neoliberal paradigm of modern Western civilization. The narrative promotes that with hard work and self-optimizing everyone can live an exceptionally (long) life.

### **4.3 Framing Extraordinary 'Old' Age: The Fabrication of George Dawson**

The last section worked with the narrative of George Dawson's life in order to show how he ages through his life-course and how this process is influenced by cultural specifics. This current section proceeds to discuss the portrayal of Dawson's extraordinary 'old' age and how he is staged as a centenarian who is not only a 'posterchild' for literacy but also for aging well. The previous chapters have shown that, comparable to Luce Irigaray's argument about women, centenarians are fabricated. This next section will argue along the lines of this fabrication and show how, in Dawson's case especially, the centenarian becomes a commodity. I will begin by discussing the means by which his extraordinary 'old' age influences the way he is treated by other people. Thereby, I will address the expectations these interactions indicate about being extraordinarily 'old' and thus what this implies about the fabrication of Dawson as centenarian. I will then address the specific fabrication of the model centenarian George Dawson from three different angles: mental fitness, physical fitness, and wisdom. I focus on the way these categories are used to establish Dawson's role model function through othering and a sense of social mobility. Finally, I will refer back to the genre of (auto)biography and discuss the ways in which the image fabricated of Dawson turns him into a sellable commodity.

Within *Life is so Good!*, George Dawson, as the protagonist and narrator, describes interactions with other people. These interactions create an image of Daw-

son as a centenarian that mirrors the expectations of the onlooker. I would thus like to argue that George Dawson becomes a reflection of what idealized extraordinary 'old' age looks like. It is because of this idealized image that selling Dawson's story works so well. This becomes especially apparent as the interactions between him and other people, tied to his extraordinary age, are openly addressed in Dawson's narrative.

Even in extraordinary 'old' age the interplay between age and race as categories of differences remains apparent. When Dawson, for instance, returns to his old hometown, Marshall, Texas, and enters the local newspaper's office, he muses that "I walked right in through the front door of the paper and somebody called me 'sir.' That's not the Marshall I knew. It wasn't just talk either. The people wanted to be helpful" (43). This multilayered statement, at first glance broaches the issue of change within the society of Marshall. Not knowing the history of the U.S. or George Dawson's origin, it would simply state that in the past, people in Marshall were a lot less polite. Knowing, however, that the changed times brought an end to racial segregation, the fact that he enters through the front door becomes a signifier for improved race relations. While when he was 21, he was a grown up and yet referred to as 'boy,' he is now called 'sir.' This, points at the decrease in racial discrimination and the changing of social roles. However, it also indicates age: a 'sir' is no doubt an adult. This double meaning of the title 'sir' points toward the markers of age(ing) that are hidden within Dawson's statement: People might 'want to be helpful' because Dawson is extraordinarily 'old.' This then would indicate respect for the elderly that trumps racist behaviors.

However, the instances in which age and race are interconnected decrease with Dawson's 100<sup>th</sup> birthday. He states that "most people only know how old I am. They don't really know me" (250). It becomes clear that people only seem to see the centenarian in him, not the person. Here, it becomes questionable whether for the reflection of the model centenarian race, gender, or class are even important. It seems as if as soon Dawson turns 100, his age status becomes more important than anything else. Surely, learning to read and write at the age of 98 was a phenomenon but then continuing to live to be 100 appears to be the factor that is most notable.

What seems to be highly important in the fabrication of the model centenarian is the emphasis on independence. Whereas Dawson is happy about the polite people in modern Marshall, he implicitly complains about peoples' tendency to be overly helpful because of his age. In that connection, he describes his relationship with Glaubman as follows: "[Richard] doesn't try to help me too much like most folks do when they find that I am over 100 years. One night he cooks dinner, the next night I cook dinner. Afterward, we do some dominoes and the loser does the dishes" (42). This statement suggests that Dawson does not need help around the house. He is perfectly capable of cooking and doing dishes by himself. He does not need the overly helpful 'young' people to do these things for him. This, again, ties

back to the successful aging paradigm and is connected to questions of elder care. As discussed in connection to Aldéa Pellerin-Cormier, the fear of a grey tsunami is oftentimes triggered by a fear of large number of 'old' people who are unable to take care of themselves. Yet, more important than not *needing* help is the fact that Dawson does not *want* any help. He is much happier if people do not constantly try to support him. In a cynical reading, one could argue that this passage works as an excuse for people to not even try to help their elderly relatives and friends. It gives those people a clean conscience who do not have the time to even offer help to 'old' people because if they had lived a life as exemplary as George Dawson, they would not want or need support.

His independence is further emphasized by a description of his activities: "Nowadays, I work hard at school. On Sunday morning, I get up and go to church. Saturday is the day that I catch up with things or maybe now that spring is coming, I'll just go fishing" (154). Dawson keeps himself busy with his education and leisure activities. He thereby stresses that, for him, 'old' age is not and never has been a 'waiting room' for death. In fact, Dawson's mortality is not addressed within the narrative. Rather, the story is future-oriented: Dawson plans to get his GED, Glaubman plans for Dawson to go on a book tour. The planning element then makes the story a progress narrative and connects back to Ricca Edmonson's concepts of a continuing "development through time" (102) in order to make a life meaningful. Dawson shows that, even, or especially, with 100, there is a purpose in his life and that he has a reason to keep going. The narrative here reverses stereotypes of expected decline and can in that sense be read as a narrative that contributes to a more nuanced imaginary of later life. This potential for nuance, however, is mostly shadowed by the neoliberal elements of successful aging interwoven within the narrative. George Dawson is allowed to break out of the 'waiting room,' into the future, in order to serve the role model function of activity and independence.

Although Dawson's years of being 'old' are part of the narrative, he is always presented in terms of progress rather than in terms of decline. Unlike Macklemore's music video, this narrative does not suggest that there is a significant break of extraordinary 'old' age versus 'old' age in terms of being freed from a culturally imagined and socially enforced 'waiting room.' Rather, Dawson seems to have skipped the 'waiting room' altogether. In Dawson's case, there does not seem to be a centenarian paradox in the first place because living like him leads to the omission of 'old' age in terms of decline and disengagement. Nonetheless, there is a slight difference in perception once he turns 100: His extraordinary 'old' age makes him more phenomenal, turning him into a valuable commodity. Moreover, the focus on his extraordinary 'old' age prevents the narrative from portraying Dawson as completely ageless. His commodification is only possible because he is portrayed as exceptionally fit at his age. This focus on his age, crucial to his commodification,

however, only appears once Dawson has turned 100. Before that, he is depicted as an example of what Katz calls “growing older without aging.” Consequently, although the narrative moves away from the stereotype of decline, it does not manage to completely abstain from a successful aging paradigm. This becomes even clearer when looking at the way the narrative emphasizes Dawson’s mental and physical fitness, as well as the portrayal of his wisdom.

### 4.3.1 Extraordinary 'Old' Age and Mental Fitness

Dawson’s ability to tell his life story is an indicator of his mental fitness. Throughout the narrative, his ability to remember details from his past are highlighted, supporting the claim of an ‘authentic’ (auto)biography: Because Dawson is able to remember, the story must be truly his. Besides the emphasis on Dawson’s general good memory, mental fitness is represented in three major points. First, Dawson is valued as a contemporary witness for the twentieth century, second, he is portrayed as a knowledgeable person whose help is needed by friends and family, and third, his ability to late life learning remains the focus in his extraordinary ‘old’ age. I will thus, in the following, give an example for each of these cases and discuss how this emphasis on his many mental abilities contributes to his fabrication as a model centenarian.

Dawson’s witness qualities for important events of world history are implied through Glaubman’s inquiries about them. He wants to know, for instance, how Dawson remembers World War I. However, Dawson does not conform to the expected answers and tells his own version of history: “I remember the year 1914 all right, but I don’t recollect any archduke or much about the World War” (65). Dawson stresses his mental capacity of remembering but not by functioning as a lay historian. He, in that sense, refrains from his own fabrication by not confirming his own historical value. Nevertheless, he stresses a different, unexpected, and maybe more important sort of value by indicating that he might not know about world history but about his personal one. Dawson explains: “‘Back in the 1920s that would have been white news. It had nothing to do with the colored.’ ‘But it’s part of American history,’ Richard said. I laughed. ‘That’s good, son. But it wasn’t part of the America I knew. If it was, I would remember’” (169). Consequently, Dawson cannot contribute to historical knowledge in a way that Glaubman expects him to. Rather, he uncovers a history unknown to normative U.S. culture. Thus, the historic value of the centenarian is increased through him not conforming to the knowledge that is passed on in history books.

Accordingly, personal history is not automatically in line with world history, and history from a person of color’s standpoint offers perspectives opposing predominantly white historical discourses. The centenarian’s narrative promises to shed light on issues of history that remain underrepresented by Western main-

stream historical scholarship. By telling his story, Dawson contributes to decentralizing history. As Takashi Shogimen puts it, there is an “anti-Eurocentric movement” that “has been gaining momentum quickly since the dawn of the twenty-first century” (324). History, as many other scholarships, has in the past predominantly looked at history from a white, heteronormative, European perspective, providing a Eurocentric view on the past. The life story of an African American can hence be read as part of the ‘anti-Eurocentric movement’ as it fosters knowledge of alternative histories. In order to become a valuable commodity, the centenarian thus needs the mental capacity to retell their life story and retell history from their own perspective. Further, the constant emphasis on Dawson’s ability to remember shows that this fact is so unlikely that it needs to be recalled various times for the reader to believe it. Here, the narrative goes against stereotypes of ‘old’ age and memory loss and establishes Dawson’s life as a counter narrative to images of Dementia.

Besides the historic value of Dawson’s mental fitness, he is experienced concerning the trivial things in life; as trivial as setting up a VCR machine. Following stereotypes of ‘old’ age, one would assume that when it comes to technology, younger generations are at advantage as they grew up with these mechanisms. Yet, Glaubman has trouble setting up the VCR because he did not read the instruction manual properly which causes Dawson to step in. After succeeding, he muses: “It’s the same when my kids are around. Sometimes, I have to wonder how they can get along without me being there to help them. But that’s okay. Even though I’m pretty busy with school these days, I don’t mind helping people” (190). Dawson is portrayed as the savior who has to help out in every area of life. For this, his mental fitness is crucial, as he needs to be mentally healthy to assist with everyday issues. This emphasis on cognitive abilities, again, implicitly refers to Dawson’s narrative as progress narrative. Instead of waiting for death, he keeps himself busy by learning and helping others. In that sense, he is portrayed as selfless: a Good Samaritan who uses all his resources to be there for others. The reader is thus not only in awe of his mental capacities but also convinced that he deserves his longevity and his health into extraordinary ‘old’ age. He did not only live an exceptionally long life by being active and staying healthy, he did so by being an extremely good person.

The third and maybe most crucial aspect of Dawson’s mental health is his ability to learn to read and write at 98. Because of his late education, he quickly rises to fame in America as the ‘posterchild for American literacy.’ Marketing his (auto)biography as co- and not ghost-written underlines the phenomenality of his efforts. Not only did he go back to school at an ‘old’ age, he has been so successful in his endeavors that he ultimately managed to co-write his own (auto)biography. This promotes his mental ability as well as it again makes a claim for the validity of the narrative: Because Dawson is mentally very fit, he is able to use his own voice to write his own life narrative. This fascination shows that the ability to learn to read and write at such an ‘old’ age is not taken for granted. Unlike the aspect of physical

fitness, the narrative does not promote this as a possible new norm for 'old' age that anyone should or could strive for. Yet, it gives the implication that only people who are cognitively able are worthy of being written about (or of writing about themselves). As it becomes clear from one of the notes Dawson receives for his 100<sup>th</sup> birthday, which reads, "I'm happy that your brain still works" (250), his cognitive abilities are not taken for granted but are certainly perceived as something to aspire to. He thus becomes not only a role model encouraging people to learn to read and write but also to generally never stop learning in order to keep one's mental abilities. As mentioned above, this emphasis on his late education also juxtaposes life-course expectations and the reality of Dawson's life.

When it comes mental fitness, Dawson's narrative undermines stereotypes of 'old' age. His mental capacities stand in stark contrast to the expectations directed towards an 'old' person. Focusing on his efforts to achieve literacy and to tell his life story becomes sellable because he is acting in a way that is age inappropriate. This denaturalization of age shows how working against social expectation does not have to result in social sanction, yet, it raises awareness. On the other hand, this positive awareness is only possible because in other instances, Dawson performs as a model 'old' person. Thus, framing him as a person of historic value and thereby buying into the stereotype of 'old' people as storytellers, the (auto)biography stages Dawson as someone who is not denying his 'old' age but simply not conforming to negative images about later life. Although the narrative thus implies that the only way to age meaningful is by keeping one's mental capacities, it also manages to establish an image of 'old' age without age denial.

#### 4.3.2 Extraordinary 'Old' Age and Physical Fitness

In addition to George Dawson's mental capacities, *Life is so Good!* emphasizes his physical fitness. Besides focusing on health and activity throughout his life, the narrative more or less subtly weaves in comments about Dawson's physical abilities in his extraordinary 'old' age. Through the focus on physical fitness throughout Dawson's life, the story becomes a manual for centenarian wannabes. The message is clear: live like George Dawson and you will be healthy until the age of one 100. More importantly for this study, the focus on physical fitness after Dawson turns 100 adds to the fabrication of him as model centenarian by juxtaposing his physical age to his institutionalized age.

Dawson becomes a 'posterchild' for active aging. In addition to the promotion of his ability to conduct physical labor until the age of 88, the narrative continues to highlight Dawson's physical fitness after he turns 100. When it comes to 'old' age and physical fitness, Sally Chivers argues that "[w]hile many are quick to assume and accept that physical disability inevitably comes with old age, others fight that connection, preferring to make sunny claims that it is possible to stay active well



into the late years" (*The Silvering Screen* 27). Both these extremes are, as it so often goes with extremes, oversimplifying the matter at hand. While presenting 'old' age as inextricably linked to disability fosters an age as decline paradigm, disregarding the biological facts of aging promotes successful aging and defines people who feel effects of aging on the body as failure.

In *Life is so Good!*, the later extreme is at hand when Dawson is offered a wheelchair at a football game, which he vehemently declines: "Let me tell you, it's a big stadium and I admit, I got a little tired. . . . Mr. Lyons, he kept trying to be helpful in the way people do. He said, 'We have wheelchairs. Let me get you a wheelchair.' . . . 'If you want to order a wheelchair that's fine. You can use it. I don't need one'" (235). This scene can be read from opposing angles. Dawson 'admitting' to be tired, on the one hand shows that his aged body is somewhat acknowledged. At the age of 100, one is allowed to be tired from time to time. This goes along the lines of the representations of the centenarian body in the previous chapters. On the other hand, the phrasing suggests that him being tired still feels wrong to him. If being tired is only marginally acceptable, using a wheelchair is presented as the ultimate failure. By insisting on Dawson's able-bodiedness, the narrative demonizes disability: Needing a wheelchair in 'old' age, equals failure at the game of aging well. Thereby, the narrative not only accuses people who are unable to walk of failed aging, it also joins in a trend to use the wheelchair as a metaphor for a life not worth living. Consequently, although the centenarian body is allowed to show signs of physical 'old' age, there are limits to the acceptance of these signs.

The narrative does not only focus on Dawson's physical ability but also on the fact that he does not need any medical attention. Apparently, he has only seen a doctor once in his life and describes the experience as follows:

"Before you know it they got me about naked except for some nightgown that don't even have any buttons in the back. Then he started in with questions, and with some questions that were none of his business. They acted like I couldn't have been alive without having seen a doctor before" (246). Unlike Aubrey De Grey, Dawson does not need biomedical enhancement in order to live a long and healthy life. In fact, he does not even need to see a doctor. Conversely, physicians seem to be in disbelief that Dawson's longevity is possible without medical attention. This scene presents a discrepancy between the demand for able-bodiedness in 'old' age and the need for medical attention to achieve it. On the one hand, it is crucial to keep 'old' people out of the hospital so that they do not overwhelm the system. On the other hand, the system only works with paying 'customers' and if everyone was like Dawson, the medical complex would collapse. At any rate, Dawson's relationship to medical profession defies stereotypical assumptions of 'old' age as a time of sickness and frequent visits to the doctor's office.

Dawson's dislike of physicians ties into a suspicion of the medical system often found in the African American community. Lindsay Wells and Ajun Gowda elaborate that

[t]he US medical institution has a long legacy of discriminating and exploiting black Americans, the haunting remembrance of which remains ingrained in the collective consciousness of the community. Historically, the medical establishment used African bodies, without consent, for its own advancement and supported medical theories, technologies, and institutions to strengthen systems of injustice.

Not trusting the medical system is thus a statistically expected behavior for an African American. In addition to showing this distrust, the narrative suggests that it is unproblematic to never consult a physician. Here, reading the (auto)biography against the grain offers insight into a common health care conundrum: In a perfect world, everybody would be healthy (like Dawson) and not need medical attention. Nonetheless, in order to catch disease early, regular check-ups are important. The narrative, in order to promote Dawson's good health, however, promotes a certain distrust in the medical system, suggesting that living a healthy life is all the healthcare a person needs. Furthermore, the narrative, once again, covers up economic factors in Dawson's life: He may have never seen a doctor because he did not have medical insurance and simply could not afford it. He therefore had no other option but to stay healthy without medical assistance. The story portrays his lack of need for it as his personal achievement and leaves out social and economic factors that may well tie into the bigger picture.

Conclusively, when it comes to physical ability, Dawson is presented as able-bodied and active. This state has been achieved by healthy living and physical activity into later life. In line with neoliberal tendencies and economic factors, going to work and conducting physical labor is euphemized into one of the reasons for Dawson's longevity. Being active, in his narrative is tied to his job, portraying him not only as able-bodied but also as economically worthy. At the same time, this disregards his poverty as the reason for his working into late life, thereby glossing over the negative effects poverty is known to have on the aging process. Connected to this, he does not need help in form of social security or any type of elder care. The age of Dawson's body, physically and mentally, is thus relatively 'young' and stand in stark contrast to his institutionalized age. While these biological capacities seem to be crucial for Dawson and his status as a sellable model centenarian, the next section discusses the role expected wisdom plays in the fabrication of a centenarian.

### 4.3.3 Extraordinary 'Old' Age and Wisdom

*Life is so Good!* establishes the connection between 'old' age and wisdom in the very beginning when Dawson's grandmother passes on her knowledge about the danger of snakes (22). The grandmother is presented as the more knowledgeable person due to her experience. As a long life inevitably fosters many experiences, the longer a person lives, the more knowledge or wisdom they presumably obtain. The reader is thus presented with the idea of respecting experiences from elders and trusting in their recommendations. The trust Dawson has for his grandmother is continued, as Dawson is supposed to be the wise person in 'old' age. As he once asked his grandmother for advice, now Glaubman asks him to share his insights about life. This knowledge is either historical content, as seen above, practical every-day knowledge as provided by Dawson's grandmother, or the answers to deeper questions of meaning and living well. The difference between wisdom in 'old' age and wisdom in extraordinary 'old' age then seems to be that the latter is supposed to entail larger philosophical and lifestyle advice on how to live a long, good, and healthy life in addition to the very practical advice on everyday life expected from the elderly. Dawson hence becomes an oracle for wannabe centenarians who are eager to learn how he managed to live this long.

Besides the obvious exchange of information between Dawson and Glaubman, which is required to write the book, Dawson also speaks about other instances in which people have asked him questions:

Lately, there be lots of folks coming to ask me questions. It's always the same questions. They want to know what I eat, what I do to stay healthy. I've done what I want and never gave it much thought. But now so many folks keep asking me why, at 101 years old, I walk just fine without a cane, I eat what I please, I have all my teeth, and my memory is fine. (41-42)

Generally, these questions again point to mental and physical fitness but the crucial point about this quote is that people ask him questions in the first place. He specifically says that the asking started 'lately,' namely after he had turned 100. The magic threshold, combined with his physical and mental abilities make him an expert on aging healthily. However, Dawson attributes his new agency and expected wisdom not only to his age but also to his literacy. He explains that "[n]ow [he is] a man that can read and for some folks that makes a difference. . . . For some folks, it made a big difference . . . when [he] turned one hundred" (243). Here, the narrative intertwines age and education. Apparently, merely turning 100 would not have been enough for some people to trust Dawson's wisdom, but since he can now read, he becomes more trustworthy. In order to be regarded as a bearer of wisdom, it is important to achieve the threshold of 100, but also to prove some level of education. Only because he is able to walk and learn, and because he has a life

experience of more than 100 years, he is considered to be wise. At first glance, the narrative here appears to stand in contrast to Aldéa Pellerin-Cormier. In "A Sunday at 105," there was a clear distinction between formal knowledge or institutionalized education and knowledge or wisdom gained through experience, suggesting that not going to school did not interfere with the wisdom of the centenarian. Yet, in Pellerin-Cormier's narrative it was also made very clear that she is literate. While both narratives suggest that life experience is more important for the imaginary of a model centenarian than a high school diploma, they also both indicate that basic education in form of literacy is needed.

The most important questions addressed to the wise centenarian seem to be the ones on how to age well. This interest does not only become apparent in life narratives of centenarians, but also in the industry of guidebooks which brought forth titles such as *Celebrate 100: Centenarian Secrets to Success in Business and Life* (Franklin and Adler) or *Healthy at 100: 7 Steps to a Century of Great Health* (Willix). Guidebooks like these are also a theme within Dawson's narrative. Interestingly, he does not seem too intrigued about their content. Yet, he ends up giving advice on the same topics these books promote. When discussing that nowadays people seek all kinds of wisdoms from advice books, Dawson criticizes: "You know what all this will do to you? 'Improve your nutrition, help balance your weight?' 'Maybe. Most likely, though, it will just make a person worry. . . . I'm healthy with what I do. I eat common food, that's what I do'" (243). This statement echoes Dawson's take on history. He might have 'achieved' what others want to achieve and is therefore expected to have a greater knowledge on dietary needs, yet, he does not tell the expected story of a special healthy diet. Analogue to his alternative knowledge on history, he establishes an alternative eating culture. He condemns the idea of the all-knowing centenarian who can share knowledge in order to help people achieve extraordinary 'old' age themselves. Rather, he claims to not even have the knowledge he is asked for. Much like Aldéa Pellerin-Cormier, however, it is difficult for him not to give implicit advice anyway. By saying that he thinks advice books make people worry, he gives the advice not to worry. Further, suggesting to do and to eat whatever suits a person is also advice in a broader sense. This notion that Dawson cannot escape his role as a wise person who is expected to teach people how to live and age well, is reinforced by him ultimately giving a detailed list of his diet (245). Consequently, even though the narrative distances itself from advice literature, in many instances, it reads like a piece of the genre itself as Glaubman asks all the questions that frequently appear in narratives on how to live long and prosper. This again points to a divided perspectives on extraordinary 'old' age: While the centenarian does not regard himself in the position to give advice, the middle-aged interviewer sparks it anyway through the questions he asks.

The third indicator of centenarian wisdom in Dawson's narrative is connected to coping with loss and grief. As a person who has outlived most of his close friends,

the centenarian is expected to have a coping mechanism at hand that can help other people overcoming the darkest phases in their lives. This aspect is also frequently addressed in advice literature concerning aging. John Robbins, for instance dedicates an entire section of his book to the topic of “The Human Spirit” and specifically writes about how centenarians deal with grief. The advice literature character of Dawson’s (auto)biography is intensified when he explains how he dealt with his daughter dying of cancer: “People asked me what did I do. Nothing to do. I just went on. Everybody has their time, and it ain’t up to me when that will be. All those times, my faith helps me going” (220). This statement resonates with Dawson’s attitude towards diet: sometimes worrying too much does not help. In line with that, he accepts that there is nothing he can do about his daughter’s condition and rather tries to ‘keep going.’ He gathers strength from his spirituality and trusts in God’s will, emphasizing the connection between spirituality and longevity discussed in the previous chapter. Moreover, his advice of not to worry about the food a person eats, is transferable to every aspect in his life. Further, his motto of always working hard and sticking to the rules resonates with his take on spirituality. Thus, if a person does their best, they can accept whatever curveball life throws at them. This serenity is portrayed as the major factor in Dawson’s extraordinary ‘old’ age.

Although all the kinds of wisdoms are expected from Dawson, he himself appears to be oblivious of his own function as a role model for aging and all other life questions. Rather, he ponders deeper questions of the meaning of his longevity and, interestingly, it is his endeavor to write an (auto)biography that seems to give him his answer: “Why am I still here?” . . . ‘I am a witness to the truth. That’s why I am still here. I can’t let the truth die with me. That’s why you’re [Richard] here: to help me get the true story down, before it’s my time” (45). This quote has several functions within the narrative. First, it advocates for the ‘truthfulness’ of the story. Second, it aims to describe the relationship between Dawson and Glaubman. They make a point of communicating that Dawson is the storyteller, whereas Glaubman is supposed to be a mere tool, required to assist in the endeavor to tell the ‘truth.’ Third, and as a consequence of the former points, this quote establishes Dawson as a figure with the power to give advice in the first place. Not only has he lived an extraordinarily long life, he is also certain that its purpose was to pass on knowledge. While he may not see himself in the position to give advice with regard to age(ing), he certainly feels that his take on history would contribute to public knowledge.

This purpose is not only met by publishing the (auto)biography. Rather, Dawson’s life in extraordinary ‘old’ age centers around giving advice. Although he is a student himself, his classmates look up to him and establish him as a role model. He is further hired by rehab facilities to talk to patients about “overcoming” (233). Although he claims not to be wise when it comes to living advice, he constantly gives it anyway. He is turned into the wise centenarian by his co-author, his teacher, and generally all people he encounters along the way. Despite his awareness of his

knowledge of the past having value for the world, Dawson himself appears to disagree on the account of his own wisdom. Dawson's presentation and his reactions show the large extent to which he, as a centenarian, is constructed into the humble figure the world would expect.

#### **4.4 African American Aging Through the Life-Course and the Fabrication of Centenarianism in *Life is So Good!***

The previous subchapters have shown how George Dawson is constructed into the figure of a centenarian that is sellable to the public. He is turned into a commodity through the emphasis on his mental and physical fitness, as well as his presumed wisdom. In that sense, he is not the author of his own life story or a person who lived to the extraordinary 'old' age of 100, he, as the protagonist of the book, is a mirror image of what society expects him to be. By being used as a living guide-book for living well into extraordinary 'old' age, Dawson becomes a commodity in Irigaray's use of the concept.

George Dawson's (auto)biography does not only show how his extraordinary 'old' age is fabricated, it also negotiates aging through the life-course with all its social and cultural implications. Dawson is aged not only by culture but also by the social structures that go along with it. In Dawson's life, cultural imaginaries and social hierarchies go hand in hand. Therefore, his aging process is accompanied by his position as an African American, poor male in the U.S. South, living through and beyond the Jim Crow era. The narrative shows how his race and class influence his aging process tremendously. Yet, by promoting Dawson's spatial mobility within the United States, it also propagates that, through the right behavior, a poor, black male can lead a good life. As he becomes a centenarian, however, the categories of race and class are only marginally addressed, and the focus lies on his extraordinary 'old' age. Here, the sense of spatial mobility is transferred onto a sense of physical and social mobility. Because Dawson is literally able to move his body as well as his mind, he learns to read and write and ultimately publishes his (auto)biography, signifying social upward mobility. The way categories of difference influence each other thus changes throughout the life-course.

In terms of the construction of age itself, Dawson's physical fitness and therefore 'young' physical age is juxtaposed with his institutionalized age. It becomes clear that through his physical and mental abilities, he is able to behave in a way that would also not be expected, considering his institutionalized age. In that sense, Dawson's example claims that a person's behavioral age is, to some extent, connected to their physical age. Only because of Dawson's relatively 'young' physical age, he is able to go back to school and learn. Another important aspect the narrative points to in terms of the construction of age is that the prevalence of one age

subcategory over another not only depends on the situation but also on the perspective of the onlooker. Dawson's father constantly highlights institutionalized age, for instance, at 12 he deems his son old enough to work on a farm. Dawson, on the other hand, does not feel ready or old enough for this new phase in his life. Further, the white woman he works for focusses on his behavioral age and connects it to racial stereotypes. Dawson, in this instance highlights his institutionalized age to expose this racial bias. Ultimately, *Life is So Good!* suggests that in the same moment, people may focus on different subcategories of age and come to different conclusions about a person's age.

The biological implications of the age(ing) body are only scarcely addressed by Dawson rarely stating that he is tired. Ultimately, the narrative often promotes a successful aging discourse, presenting Dawson as a model figure that, in terms of the aging process, is worthy of being looked up to. The discrepancy between the emphasis on physical fitness in this narrative and the more nuanced depictions within "Glorious" and "A Sunday at 105" suggests a reading in terms of race and gender. Dawson, as a male maybe needs to be portrayed as financially independent and hardworking into 'old' age, whereas the same imaginary of success is achieved by women as long as they are able to keep their house clean. Moreover, Dawson as an African American may have to perform progress even harder than the other two individuals discussed in the previous chapters because becoming a role model in the U.S. as a black person requires perfect behavior. In order to upkeep the imaginary of Dawson as a "self-made man," it thus becomes necessary to portray him as independent and hard working as possible, even in extraordinary 'old' age. While issues of race and class are thus not directly addressed once Dawson has turned 100, this reading shows that implicitly, these differences do not disappear. Rather, the attention shifts, and extraordinary 'old' age becomes the focal point. In that sense, Dawson, as well as Helen and Aldéa Pellerin-Cormier, becomes another 'other,' as his extraordinary 'old' age becomes the defining factor of his representation.

In promoting a discourse of active and healthy age(ing), *Life is So Good!* shows certain markers that are common for many centenarian narratives, most prominently discussions about health and lifestyle. While Dawson, as Aldéa Pellerin-Cormier, seems reluctant to serve as a beacon of wisdom for these issues, he is still staged as a model in aging well. His narrative is then one of successful aging with the addition that the successfully aged individual does not necessarily regard his aging process as a success. Nonetheless, the emphasis on his extraordinary 'old' age shows that centenarians are by no means regarded as ageless, as at least his institutionalized age is constantly highlighted. The discrepancy between Dawson's self-perception and the way he is framed through Glaubman's questions again points to the assumption that the middle-aged co-author may promote cultural imaginaries he would expect from a centenarian, while the centenarian himself refrains from tying into binaries of success versus failure. By the fabrication through the nar-

rative, however, Dawson is also imagined as romanticized other 'other' who goes beyond the expectations for 'old' age but not strictly presents a continuation of the midlife.





## 5 Representations of Extraordinary 'Old' Age: Same, Same, but Different?

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In the past three chapters, I have outlined how centenarians are staged as a distinct age group of extraordinary 'old' age which is separated from 'old' age in various ways. The most prominent aspect is that all the narratives discussed reflect an inherent fascination and commodification of extreme longevity. The number 100 as threshold to a stage that exceeds mere 'old' age, appears as a desirable goal for every individual to reach. The concept of age is then made visible through an institutionalized age that exceeds the expected norm of the life-course.

In Macklemore's music video to the song "Glorious," featuring his grandmother Helen, the centenarian is portrayed as a form of the 'other' not only to midlife but also to 'old' age. I have therefore traced how through the sensationalized way her behavioral age is staged, as well as through the lyrics of the song accompanying the video, Helen is imagined as an other 'other,' inviting the audience to think of centenarians as their very own category within the life-course. Aldéa Pellerin-Cormier presents a more subtle imaginary that, on the one hand, ties into stereotypes of 'old' age but, on the other hand, paints a picture of a centenarian's life that is defined by in-betweenness rather than binaries. This effect may well be due to the different perspectives traceable within "A Sunday at 105": That of the middle-aged director, echoing the media images of centenarians and successful aging, and the one of the centenarian herself, providing a more nuanced representation by refraining from tying into some of the stereotypes expected from her. Lastly, George Dawson is presented as not only a 'posterchild' for literacy but also a 'posterchild' for living and aging well. With a focus on his ability to achieve literacy at the age of 98, as well as being able to write down his life story, the focus here lies in high performance especially in terms of mental aging. Moreover, Dawson's narrative has made explicit when and how categories of difference, such as age, race, and class, interact with and trump one another.

The fabrication of centenarians thus imagines them as still very much a part of society and not disengaged from it. Rather, they are culturally constructed as wisdom-bearing role models who take up an advisory position for younger generations, including those currently considered 'old.' At the same time, the centenari-

ans tend to distance themselves from this supposed social role, as well as from the cultural imaginary it is based on. The biological aspect of age(ing) is linked to the role model function ascribed to centenarians. Although the cultural imaginary requires an able-bodied centenarian, they are presented as physically 'old' from time to time. This then counters the supposed indivisible link between 'old' age and disability without explicitly denying the biological facts of age(ing).

The extraordinary institutionalized age of 100 provokes awe within mainstream society. In many ways, outward age, behavioral age, and physical age become secondary to the construction of centenarianism, as the number 100 appears to bear all the defining power. While centenarians are thus too 'old' to even exist in the public imaginary and therefore become a phenomenon, they are allowed to show physical weaknesses and still be considered role model figures. Nonetheless, neither of the centenarians depicted show physical or mental signs of aging that go beyond being tired or needing a walker. If centenarians are too old to exist in public imaginary in the first place, even with these minor signs of aging, their physical age is depicted as younger than their institutionalized age. At the same time, the phenomenon of centenarianism is frequently emphasized through the juxtaposition of institutionalized age and behavior. Wherever the behavior of a centenarian does not align, interest is generated. This goes especially for Helen's youthful activities and Dawson's late education. Going beyond the expected behavioral age is, as the narratives suggest, only possible because of the remaining physical and mental fitness. Through the positioning of the centenarians as role models of age(ing), as well as through their extraordinary 'old' age in the first place, the stories are thus still somewhat connected to and sometimes even defined by a successful aging paradigm.

Every narrative discussed in the last three chapters contains aspects of successful and active aging. At the same time, they all overcome the paradigm at certain points by, for instance, portraying the centenarians as weak and tired or in need of assistance. Thereby they show, on the one hand, that being a role model in aging is possible without being perfect and that being 'old' (especially physically) is also acceptable. On the other hand, the fascination with centenarians in the first place is of course due to the imaginary that they have aged successfully and can presumably help others to do so as well. In that connection, centenarians are expected to perform age in a certain way, namely active and successful in body and mind. While in parts, the centenarians discussed here seem to go against this performance, as a whole it is ever-present within the narratives. While the institutionalized age of 100 as a benchmark invites a cultural imaginary of successful aging, the number is always part of the story, deeming the narratives not entirely ageless (cf. Katz). This then distances centenarian narratives from a successful aging paradigm in the sense that they are growing older, at least in institutionalized age, instead of being entirely ageless. Nonetheless, with the 'success' in institutionalized aging comes

the expectation to be successful in other age categories, as well, as we are prone to believe that the age categories need to align for a naturalized performance of age. On the other hand, the centenarians themselves counter this understanding, oftentimes breaking with the cultural imaginary at hand and the performance going along with it.

It is therefore too simple to dispose narratives of centenarians as mere amplifications of a successful aging paradigm. Nevertheless, there are those centenarians who are depicted and those who are not. Dementia, for instance, appears to be an uncrossable red line, as well as needing a wheelchair. The imaginary of the centenarian is thus very exclusive. While the centenarians depicted attempt to narrate their own lives with nuance and meaning, refraining from successful aging tropes, the selection of people depicted by the middle-aged producers of the narratives reinforce the paradigm.

In all three cases observed, we can assume a form of double oppression. While the white female centenarians cannot get over the stigmas of gender roles in terms of relationships and sexuality, the African American male centenarian has to overperform the centenarian role in order to remain a role model for mainstream society. Presentations of extraordinary 'old' age may here attempt to portray centenarians as one new age group by stressing commonalities, reading these narratives against the grain, however, shows that overall social structures are always part of the cultural representations, as well. That is, being a centenarian may get an individual out of the 'waiting room' of 'old' age in public perception but only if it is performed in the right manner. The requirements for this performance differ according to the social status of an individual and the cultural imaginaries that go along with it.

These issues show how complex age(ing) socially, culturally, and biologically is, and that a discourse reflecting this complexity has yet to be established. Connected to this, the centenarian narratives discussed here show that the expectations of what a centenarian is supposed to be like, imagined by 'young' people, are not always shared by the centenarians themselves. Read against the grain, they rather show the complexity of late life, especially when the centenarians get to speak and visibly break with the expectations of their co-authors/producers. In these instances, it becomes apparent that by trying to make sense of something they do not fully understand, people are inclined to establish master narratives that conform with their expectations of life itself. What engaging with centenarian narratives shows, however, is, that these master narratives of aging are much too simplified to fulfill the purpose of making sense of extraordinary 'old' age or the construction of age in general. Relating this back to 'old' age, one message this discussion drives home is that there is a need to listen to 'old' people in general, not only those who have crossed the magical threshold of 100, in order to recognize the complexities of their realities. This very simple paradigm is widely accepted within aging scholar-

ship, yet, in popular media, 'old' age is more often than not represented as a mere stereotype. The same would happen to the representation of centenarians, if it was not for the few moments in which they are allowed to speak for themselves.

The fabrication of centenarians works against images of isolation and disengagement in later life. As especially Dawson's narrative works against the centenarian paradox by indicating that the social status does not tremendously change once a person turns 100, he advocates for aging as a continuum. Everything that is supposed to be possible for centenarians should also be possible for everyone, despite their age. In that connection, the narratives discussed here advocate a meaningful late life especially through a sense of purpose and future, but also by stressing family relations and community. At least, if not depicting general 'old' age, centenarian narratives raise the question of what happened before their subjects made it to the 'finish line.' Certainly, for the individual, the institutionalized age of 100 did not bring back their meaning in life. Rather, these narratives suggest that there can be meaning and meaninglessness in all stages of life. However, society refuses to look at certain age groups, deeming them invisible.

In all three cases discussed, the juxtaposition of age categories leads to the questioning of stereotypes of 'old' age and therefore to a sense of the other 'other.' This subversion supports claims like 'you are only as old as you feel' or 'age is just a number.' Looking at the fact that all three narratives heavily rely on the emphasis of their subjects having crossed that threshold into centenarianness, it becomes clear that the number 100 plays a significant role in the subversion of these stereotypes. Here, the threshold of 100 seems to be important as it appears to let people go beyond many social, cultural, and biological expectations. The institutionalized age of 100 seems so incredible that any type of action becomes a juxtaposition to the expected and naturalized norm. The mere existence of the centenarians portrayed hence puts them into a role model function. Consequently, other than in many narratives of decline, the focus is not on the biological restrictions of physical age, rather on the beauty of life itself. Hence, becoming a centenarian, according to the narratives discussed, evaporates many stigmas that come with 'old' age.

Nevertheless, focusing on these three narratives, as well as guidebooks and commercials, only provided a look at those centenarians who are able and allowed to tell their tales. The danger of these narratives, as much as they can show the beauty of life in later years, is that they gloss over the fact that not every 'old' person is able to sing karaoke, has the ability to see their family regularly, or has the mental or physical ability to speak about their lives. As the people who lack these abilities rarely exist in popular narratives, it seems easy to forget about them. In order to establish a better view on the centenarian demographic, it would be desirable in the future to seek out exactly those people whose stories are not told. For this study, dealing with representations, it is unfortunately impossible to cover this

ground. It is important, however, to bear in mind that there is a large discrepancy between those who are represented and those who are not.

While the narratives discussed here thus have a lot in common in terms of presenting extraordinary 'old' age, they all remain individual stories, getting to the core message of centenarianness from different angles. Most interestingly, all centenarians come from very different cultural backgrounds: two female, one male; two white, one black; two U.S. American, one Canadian. While these categories of difference in gender, race, and region certainly play a role within the individual narratives, they do not significantly alter the overall imaginary of the centenarian. That is, although the African American centenarian has to appear even more perfect to be a role model and the female centenarians are denied a sense of sexuality, these restrictions do not seem to influence the way their extraordinary 'old' age is presented in general. All three individuals are hence staged as centenarians first and as female, male, black, white, rich, or poor second.

Ultimately, being a centenarian does not seem to matter too much to the centenarians themselves. They do not regard themselves as extraordinary in any way. For them, institutionalized age does not appear to be overly important. For the younger generations, on the other hand, it appears difficult to imagine individualism *in* and a nuanced perspective *on* any kind of 'old' age. Looking at centenarian narratives drives home three major points: First, by being 'aged by culture,' we come to expect certain images of life stages which influence our storytelling. Second, 'young' people imagining how it is to be 'old' or extraordinarily 'old' are very much taken up by these life-course imaginaries, often restricting them from telling stories of nuance in 'old' age. Third, only those who experience 'old' age or extraordinary 'old' age are able to, at least partly, question the cultural imaginary they are supposed to find themselves in. This calls for more diverse stories of age(ing) and later life written by those who have experienced 'old' age in the first place.

This first analytical part of the study has shown that when it comes to a meaningful life in 'old' age, social, cultural, and biological factors intermingle to create the concept of age. However, all centenarian narratives looked at here are united through the absence of disability or illness, echoing the wish to regard age as primarily constructed socially and culturally, rather than as a biological reality, as well. The sense of the biological aging process was only marginally addressed within this part of this book. Activists and scholars alike have tried for decades to remove the stigma from illness and disability. While fighting for the acknowledgement that with a condition that would be considered outside the norm or even with a terminal disease, life can be meaningful at any stage, these stigmas seem to come back with a vengeance in 'old' age. Accordingly, representations of 'old' age in general and extraordinary 'old' age in particular are only considered to be meaningful as long as illness and disability remain absent from the narrative. Therefore, society

only admires those centenarians who got there without falling ill, the others are not part of the public image of the centenarian as paragon of aging.

Bearing the lack of illness and disability in narratives of extraordinary 'old' age in mind makes it all the more interesting to think about the question of what happens when age truly is an illness. Therefore, the next part of this study will focus on progeria, an aging disorder that has people's bodies age significantly faster than would be considered normal. Here, aging becomes illness and is therefore regarded in a different way. Like centenarian narratives, narratives of children with progeria denaturalize age(ing) and thus make visible the underlying constructs of how it is negotiated culturally, socially, and biologically.

### **III. Hutchinson-Gilford Progeria Syndrome—Questioning Assumptions of Age(ing)**





People with the rapid aging disease Hutchinson-Gilford progeria syndrome (progeria), are not as visible in everyday media as centenarians are. Especially due to the low number of worldwide people living with the condition—as of January 2022, the Progeria Research Foundation (PRF) reports 132 known cases—the disease has only gained public interest during the last decade (“Meet the Kids”). Nevertheless, compared to the rarity of the disease, there is a rather high number of narratives that find their way into public media. There are newspaper articles, *YouTube* videos, social media performances, documentaries, and full length (auto)biographies, as well as a large variety of scientific publications. The scientific engagement with progeria seems to have two main aims: either to find a cure for the disease or to find a ‘cure’ for aging in general. While non-scientific discourses provide insights into life with the condition, the search for a cure is a strong presence within these narratives as well. Therefore, the topics of everyday life and scientific research are often intertwined in almost all progeria narratives.

Within the scientific discourse surrounding progeria, researchers ask questions about the connection between the condition and the average human aging process. Burtner and Kennedy point out that “[o]ne of the many debated topics in ageing research is whether progeroid syndromes are really accelerated forms of human ageing” (567). Progeria syndromes are thus researched in order to find out how understanding the disease can help unravel the mysteries of human aging in general. Burtner and Kennedy continue to explain that,

[e]xciting recent findings regarding a severe human progeria, Hutchinson—Gilford progeria syndrome, have implicated molecular changes that are also linked to normal ageing, such as genome instability, telomere attrition, premature senescence and defective stem cell homeostasis in disease development.” (567)

Hence, there is a similarity between the progeria body and the aging body which, medically speaking, makes progeria an interesting point of inquiry for biological research on age(ing). The theory inherent in this biological research is that, once there is a cure for progeria, this cure might also slow down the ‘normal’ aging process. This theory is used by the PRF to advocate for support in finding a cure for progeria. It says on the PRF homepage that “there is clearly a tremendous need for research in progeria. Finding a cure for progeria will not only help these children but may provide keys for treating millions of adults with heart disease and stroke associated with the natural aging process” (“Progeria 101”). The strategy of the foundation is thus clear: besides evoking compassion for children with progeria, the homepage also elaborates on how supporting progeria research will not only benefit people living with the disease, but also the general population. Here, the PRF ties into the discourse used by the SENS research foundation, advocating a ‘cure’ for aging.

When it comes to progeria, the scientific discourse of how to find a cure is always connected to the non-scientific one. Besides advocating the search for a cure and therefore dealing with the biology of the condition specifically, these non-scientific narratives also provide insight into the cultural construction of progeria as an extraordinary form of aging, as well as the social roles children living with the condition are presented in. Because awareness for the disease has emerged fairly recently, progeria, like centenarianism, used to be a cultural blank sheet that has only started being filled within the last decade.<sup>1</sup> Hence, the increasing number of recently emerging narratives has defining power over the way the condition itself as well as its implications about human age(ing) are presented to the world. The non-academic narratives dealing with the topic follow a limited number of individuals, as there are assumably only a very few people who are willing to make their lives with the condition public. The number, in fact, is so small, that the PRF introduces many of them on their homepage. The total of 26 children represented by the PRF, as of 2022, are introduced with short bios and are those who are more or less frequently presented in popular media (“Meet the Kids”).

At first glance, texts on children with progeria appear to be fundamentally different to those on centenarians, however, looking closer reveals many commonalities between the discourses. For narratives about centenarians, the core question seems to be ‘how can I become one of them,’ whereas articles on progeria implicitly pose the question ‘how can I help them?’ A common reference in progeria discourses is, for instance, the lack of a cure. In an article for *ABC News*, Joseph Diaz writes that “there was no known treatment for progeria and no cure, leaving [families] to care for their beloved baby, whom they knew they would lose too soon.” This rather emotional narrative may evoke sympathy, leaving the reader with the notion that these children and their families need help.

Although, both centenarian and progeria discourses pose different questions, they can be accused of deriving from the same interest in expanding the human life span. Both, the interest in imitating centenarians and the wish to help children with progeria, are related to a biological understanding of the aging body, asking how this biological process can be stopped or slowed down. Furthermore, narratives about centenarians, as well as about children with progeria relate to a certain amount of awe. Either, because a person has managed to live extraordinarily long or because a ‘young’ person lives in an extraordinary ‘old’ body.

Related to the search for ways to increase longevity, the direct connection between progeria and ‘old’ age is another common trope in discourses about the disease. Mia Graaf suggests in a *Daily Mail* article that there are new developments in

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1 The interest in centenarians emerged earlier, providing about two decades of narratives by now. Nonetheless, the phenomenon of centenarian narratives can still be regarded as a rather recent one.

age(ing) research owed to the efforts to find a cure for progeria. She writes that a “breakthrough came as a surprise to researchers who were investigating a cure for progeria, a genetic disorder that causes children to age rapidly and die before they reach their late teens.” Graaf not only directly connects the progeria body to the aging body, she also refers to the benefits progeria research may have for the general population. Thereby she reveals a pitfall of the discourse: children with progeria are prone to be imagined as human guineapigs whose stories are only noteworthy, because they may ultimately lead to a ‘cure’ for aging.

Consequently, both, discourses of centenarians and children with progeria, tap into fears of the aging body and imagine people who live with it as inspiring. Both centenarian and progeria narratives connect the biological with the cultural and the social; yet, the two phenomena, represent different core assumptions. Centenarians are presented in light of an absence of disability and illness, suggesting that one can only be a star of aging when physical signs of ‘old’ age remain mostly absent; with progeria, age(ing) is the illness. Discussing progeria hence offers a new angle on questions concerning the way age is culturally, socially, and biologically framed in Western societies. One of the overarching questions of this study remains what constitutes a definition of ‘old’ age and which age subcategories are more dominant in which situations. With regard to progeria this question becomes especially interesting because age subcategories are juxtaposed to an extreme. This rare condition then offers insights into cultural constructions of age by juxtaposing its cultural, social, and biological dimensions.

Despite many differences, the connection between centenarians and children with progeria can be drawn with regard to the biological interest concerning the aging body: Both are studied in terms of their extraordinary aging process, in order to find answers for the biological aging process in general. Furthermore, all these bodies and stories are met with fascination and interest. Because they tell the story of processes that are considered to be extraordinary, the public is inclined to look. Therefore, despite all the differences, there is a point of comparison between centenarians and children with progeria as both present age(ing) in a way that challenges social roles, as well as cultural and biological imaginaries.

While the previous part focused on extreme longevity and the way people come to terms with the aging process in these extraordinary cases, this second section will deal with the way ageing is perceived when it is accelerated. What happens if one does not look back on an extremely long life but rather has to deal with the fact that life is considerably shortened? How does this altered temporality of a life influence the way the life-course is defined? What are the signifiers for age(ing) when the process denies every expectation fostered through public imaginaries? Finally: How do social, cultural, and biological norms work together in order to foster age(ing) imaginaries or even question them? Ultimately, a discussion of progeria, as an extraordinary form of age(ing) can contribute to the field of aging studies in

general by making visible numerous aspects of the interplay of age subcategories in terms of culture, society and biology that work together in order to form a cultural understanding of what age(ing) is. Through this visibility, in turn, the condition allows a closer look at the contexts in which a certain category of age becomes important for the definition of age as a whole.

Progeria narratives are not only narratives of extraordinary age but also of illness. Ann Jurecic explains that what “medical humanities defines as ‘illness narratives’” are “autobiographical accounts of illness spoken or written by patients” (2). Although the accounts looked at in this section are not strictly autobiographical, they are all narratives of and about people who can be defined as patients. Jurecic continues to explain that illness narratives are

the consequence of a variety of changes in culture, medicine, media, and literacy over the past century, which include medical professionalization; the rise of modern health care; the emergence of the women’s movement and the gay rights movement; the etiology of the AIDS virus; the inability of master narratives to give meaning to suffering in the modern era; and technological advances that promote self-publication and the global distribution of information. (10)

The most important factor here, I would argue, is the lack of master narratives dealing with illness. During the second half of the 20<sup>th</sup> century, society moved away from conformity and embraced individuality, a concept that also left room for imperfection. Being ill became something people could and should think about in order to try to make sense of suffering and death through writing. Although this movement, away from the norm, began decades ago, today, society still struggles with things that are outside of this norm, especially when it comes to the human body. In that connection, Elizabeth El Refaie argues that “[t]he very notion of ‘normalcy’ in relation to our embodied existence is problematic [as] it disregards the experiences of disabled people” (2). In other words, by propagating that the human body can have a state that is ‘normal,’ the experiences of those who are not considered to be part of said norm are left out of the picture and are simultaneously devalued.

Disease, according to El Refaie is one of the things that moves the human body suddenly far away from a constructed norm. She argues that “the experience of disease fundamentally unsettles our usual relationship with our bodies and in doing so changes our thought patterns” (5). Disease or disability then present a rupture in the way people regard themselves. Illness narratives, in turn, are a means to cope with this new sense of not belonging to a norm anymore and finding meaning within this new framework of life. In case of progeria, however, the children affected by the disease do not experience anything other than having a body with progeria. Here, the unsettling takes place for the parents who imagined having a child with a ‘healthy’ body. They then have to come to terms with the new informa-

tion whereas the children themselves grow up with the experience of a deviating body. Therefore, this section will focus on the perspectives of the parents and how they come to terms with the new knowledge of having a child with progeria as well as with the perspectives of the children, who grew up with this knowledge but have to cope with the deviating body.

In that connection, it is fruitful to consider Elisabeth Kübler-Ross' "five stages of dying," or stages of grief—denial and isolation, anger, bargaining, depression, and acceptance (11). As progeria shortens the life expectancy of a person significantly, children and their families need to come to terms with the thought of a premature death. For parents, this awareness comes with the diagnosis, for the children it is established, when they are considered 'old' enough to cope with the information. Kübler-Ross' stages serve as a tool in order to navigate where the subjects of the individual narratives locate themselves in this process.

In light of the framework of illness narratives, this Part C will engage with questions about the interconnectedness of age and disease. Or more specifically, what happens when age is the actual disease? How do the narratives by children with progeria, who have lived with the condition their entire life, differ from the narratives by their loved ones?

Although this section deals with a fundamentally different form of extraordinary age(ing), mechanisms and topics such as age(ing) and gender, physical age and systems of care, or age(ing) as a phenomenon occurring within progeria narratives are very similar to those discussed with regard to centenarians. My analysis of progeria narratives will thus always be tied back to my readings of centenarian narratives in order to find similarities and differences. The aim is to reread the finding of both sets of narratives through each other and find out where an analysis of one can lead to a better understanding of the other.

Within this section, I will look at three narratives about and by children with progeria: the short documentary "Living With Progeria: Born Different," introducing three children with progeria of different ages and backgrounds, hence giving an introduction to the topic; the HBO documentary *Life According to Sam*, granting insights into the experience of one single child but also focusing on medical trials for a progeria treatment and therefore on the biological implications of the condition; and, finally, *Old Before my Time*, a full length written (auto)biography by Hailey Okines and her mother Kerry Okines, discussing the social implications of progeria for an individual as well as a family as a whole. The three examples are chosen to be somewhat analogue in terms of media format, to the examples used in part B. Thus, I am analyzing a widely seen medial example, fueling the phenomenon ("Living With Progeria: Born Different"), a documentary, presenting every-day life with an extraordinary form of age(ing) (*Life According to Sam*), and a co-written (auto)biography, giving the possibility to study a different genre and varying challenges of narrative structures (*Old Before My Time*).

The first chapter of this part will focus on the short documentary “Living with Progeria: Born Different.” This section will deal with the condition as a phenomenon and the fact that popular videos, such as “Living with Progeria” tend to make a spectacle out of everything outside the norm. I will trace how children with progeria and their aging process are framed as ‘different’ by modern media and ask how they, themselves regard their aging process.

The second chapter, focusing on the HBO documentary *Life According to Sam* goes into detail about progeria as a medical issue. While it focuses on the biological, it narrates how the aging progeria body may affect social realms of a life and ultimately contribute to a cultural imaginary of the condition in particular and age(ing) in general. I will trace the meaning of age(ing) as a disease and the implications this narrative may have on the popular discourse around ‘curing’ the aging process. Furthermore, the chapter discusses age, disease, and meaning, as Sam Berns is not only known for this documentary but also for his TED talk, dealing with the recipe for being happy in life.

The final chapter of this section is the only one dealing with a full-length (auto)biography: *Old Before my Time: Hayley Okines’ Live with Progeria* by Haley Okines and her mother Kerry Okines, co-written with Alison Stokes. Comparable to the discussion of Dawson’s *Life is So Good!*, this chapter deals with the question of agency in co-written life narratives. Moreover, as this is the only narrative presenting a full account from birth over diagnosis into Okines’ teenage years in detail, this last chapter focuses on how age in connection to illness is discussed from the very beginning of life.

## 6 Sensationalizing Disease: “Living with Progeria: Born Different”

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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 performing 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.<sup>1</sup> 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.

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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 Adalia 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!" (@adaliao6).<sup>2</sup> 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:

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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,<sup>3</sup> 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

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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<sup>4</sup> 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.<sup>5</sup> 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

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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 Rose's 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<sup>6</sup> 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

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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<sup>7</sup>—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

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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 Rose’s 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."<sup>8</sup> 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

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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.<sup>9</sup> 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.<sup>10</sup> 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

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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.<sup>11</sup>

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

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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 Michiel's 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<sup>12</sup> 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

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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 commonalities, 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.



## 7 Sam Berns: Progeria Between Clinical Trials and Lived Experience

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The last chapter has given an overview over three different children living with progeria, suggesting that popular documentary may promote what I call successful impairment as an analogue concept to successful aging. This concept is taken up again in this chapter as I explore the construction of age(ing) as it connects to progeria. I focus on the 2013 HBO documentary *Life According to Sam*, depicting Sam Berns, a teenager with progeria from Boston. Here, the medium presents a crucial difference to the discussion of “Living with Progeria” in the previous chapter. While both sources are marketed as documentaries, “Living with Progeria” merely provides short five-minute glimpses into the individuals’ experience. Contrastingly, *Life According to Sam* is a full-length documentary, really zooming in on Sam Berns’ life, including his social and medical surroundings. *Life According to Sam* provides a subtler approach to living with progeria, trying to normalize life with the condition instead of pointing at its ‘difference.’ At the same time, the film raises awareness for the condition and presents itself as an advertisement for the PRF. It could then be accused of commodifying Berns in order to promote the research for a cure for progeria.

Much like the Vandeweert siblings discussed in the previous chapter, Sam Berns takes up the social role expected from a person whose institutionalized age moves within the teenage years: He is a student in junior high school, which dictates the way his stage in life is culturally imagined, as well as the social role he performs. Because of his aged body, on the other hand, the documentary portrays him as highly medicalized. It therefore depicts an area of extraordinary age(ing) that is often neglected within centenarian narratives and has only been touched upon in the previous chapter: Age and the biological, as well as the extraordinarily aged as a patient. *Life According to Sam* serves as an entry point to the inquiry of the biological as inextricably linked to social roles and cultural imaginaries. The connection between the cultural, the social, and the biological is especially prevalent in Sam Berns’ narrative as his parents are pediatricians and the founders of the PRF. They establish clinical trials and make it their goal to find a cure for progeria. This process is part of the documentary and provides insight into the connection between



the biological realms of Berns' aged body, its medical implications, and the way they affect his role in society, as well as the cultural imaginary attached to progeria.

Furthermore, *Life According to Sam* introduces a caretaker into the equation of extraordinary age. Whereas care persons were only marginally present within centenarian narratives (cf. Aldéa Pellerin-Cormier's daughter bringing her food), "Living with Progeria" touched upon the issue of care, especially in the part concerning Adalia Rose and the protective infrastructure surrounding her. The depiction in these instances, however, remained superficial, not elaborating on structures of care and the challenges an aged body may pose to everyday life. Contrastingly, in *Life According to Sam*, Berns' caretaker, his mother, is not only presented as his personal caretaker, but also as a savior and mother figure to all children with progeria. Consequently, she represents a core U.S. American ideal of motherhood and care taking, not only for her own son, but for an entire 'nation' of progeria patients and their families. The documentary renegotiates care as a public good but also raises questions about care and expectations of care not only concerning children with progeria but also 'old' people in general. The connection between Berns and his mother, as well as the fact that his mother runs the PRF and the first progeria drug trial, again, raise questions of age, agency, and disease: Is *Life According to Sam* truly his narrative or is he staged through the perspective of his mother and the PRF?

Within this chapter, I will explore how age is culturally constructed through its various subcategories, care, and medicine in *Life According to Sam*. Thereby, I will put a special focus on the depiction of the medical implications of the condition and therefore on children with progeria as patients. Furthermore, I will discuss how the documentary presents Berns as a child with progeria within the context of the search for a cure as an economic endeavor. First, I analyze the portrayal of progeria and the way it challenges dominant discourses about age(ing). I will then look at the connection between premature aging, aging in general, medicine, and the portrayal of Sam Berns' life within these categories. Subsequently, I will look at the clinical trial for a progeria treatment, inquiring how Berns' role as a patient influences his identity, as well as how the search for a treatment helps to stage progeria as an inclusive, transnational issue that concerns everyone. Lastly, by comparing the message of Sam Berns' TED Talk "My Philosophy for a Happy Life" to the way he is presented in the documentary, I will discuss the question of agency within the production of the documentary and its surrounding texts. Here, I will focus on the ways thinking about agency adds to a broader understanding, not only of the narrative itself but about its implications for the aging process.

## 7.1 Extraordinary Age in Life According to Sam

As discussed in the previous chapters, extraordinary forms of aging make age more visible in general by denaturalizing the narrative, that is, by deviating from the expected process and providing a surprising take on something that people take for granted. Progeria contributes to this denaturalization not only by disrupting normative expectations of the aging process but also by juxtaposing the different subcategories of age. Hence, progeria makes these subcategories visible and shows the circumstances in which one may be more important to an individual or the onlooking society than others. While these negotiations were present within all previous chapters, *Life According to Sam* allows for a more detailed examination, as the documentary often specifically addresses these juxtapositions. Because physical and outward age do not align with behavioral and institutionalized age, the case of Sam Berns serves as a point of inquiry for the observation of the interplay between different age subcategories in order to explore which subcategory has the power to determine a person's age in different situations. *Life According to Sam* portrays Berns' everyday life and the way he copes with his condition in various different settings. By challenging the way age is naturalized, his story questions the way age, and especially 'old' age, is culturally constructed in Western societies.

Berns' family's approach to progeria is established at the very beginning of the documentary through his father, who says "[w]e're well aware of the prognosis [of progeria] but, you know what, we're gonna stay optimistic because why wouldn't we be? I mean, what are we gonna do? Like go into a shell?" (00:05:45-00:05:58). This attitude toward progeria sets Berns and his family apart from approaches to 'old' age. Although they know that the remaining life span is limited, they refuse to enter a 'waiting room' for death. Moreover, there does not appear to be a protective shell surrounding Sam Berns. While the narrative points to his physically aged body, it, at the same time, emphasizes that he and his family refuse to be defined by the cultural imaginaries that go along with it.

Similar to Adalia Rose, the first impression the audience gets of Sam Berns is, as it often is in every-day encounters, a visual one. Berns' portrait is featured on the documentary's DVD cover where he appears frail, has wrinkles, is bald, and wears glasses. Nonetheless, he is smiling and seems to be happy. His outward attributes taken together are visual indicators usually associated with an 'old' body. It is the appearance that causes the viewers to make initial assumptions about Berns' age. Without any further information, the spectator relies on the information given through his outward appearance. Consequently, because wrinkles and frailty are associated with 'old' age, he would most likely be categorized as such or at least not as 'young.'

The DVD cover, at the same time, already indicates the reason for Berns' outward appearance as not being 'old' age but progeria. It says on the cover "progeria

is just a part of who I am.” Although no explanation is initially given about what progeria is, a hint is provided in connection to a disclaimer: The cover clarifies that the condition is just a part of Berns, indicating that for him at least it is completely normalized. This disclaimer is complemented by his smile, emphasizing his contentment with his situation. Judging the documentary by its cover would then suggest a less sensationalist approach to progeria than we have seen in “Living with Progeria.” Instead of focusing on what is distinctly ‘different,’ *Life According to Sam* seems to focus on progeria simply as a part of life.

Although Berns’ outward features are clearly caused by progeria, the film clarifies in its first minutes that “[w]hat is aging in Sam, is aging in all of us” (00:03:07). His disease does not only give him the visible features of an ‘old’ man but also weak bones, arthritis, and a cardiovascular system that would be expected in a person who has reached the institutionalized age of at least 80. This connection between progeria and the conditions associated with the ‘old’ body appears to be deliberately placed as it serves the purpose of promoting progeria research, which presents to be a crucial aspect of the documentary and will be further discussed in chapter 7.2.

Sam Berns’ body is put into the foreground again during the very first scene of the film where his aged hand is shown in a close-up shot as he plays with Legos (00:00:51). This shot can be read in two different ways. First, it can be seen as a juxtaposition of the aged body with ‘young’ behavior. His wrinkled hand, showing signs of arthritis, would be assumed to belong to an ‘old’ person, whereas playing with Legos is generally regarded as a children’s activity. In that sense, the action of engaging in a children’s activity would question the initial categorization of Berns as ‘old’ according to his physical and outward age. Hence, reading the scene in terms of the juxtaposition of age categories shows how different environments can emphasize different aspects of the constructions of age, questioning Berns’ initial appearance as ‘old.’ This reading is made more complex when thinking about the size of the Legos Berns works with. He puts together rather small parts which, if they were put together by an institutionalized aged person, would probably be considered a job well done and fall under the category ‘look at what this person is still able to do’ as seen in many centenarian narratives. The mere size of the Legos sparks the imaginary that what Berns does in this scene is not only unusual for an ‘old’ person but also mostly impossible. Berns’ body may be physically ‘old,’ yet, there is also an underlying emphasis on the things he can do despite his aged body which reminds strongly of centenarian narratives.

This ability of Berns’ body is connected to the second possible reading of the scene: It derives from the fact that playing with Legos could also be a therapeutic method to keep the arthritis-affected joints mobile. In that sense, the image of a hand that looks wrinkled and therefore ‘old’ could also be read as a promotion of the prevalent cultural imaginary of ‘old’ age as a phase of ‘second childhood.’ This phase of the human lifespan, according to Andrew W. Achenbaum, “signifies

diminishing physical and intellectual faculties with advancing years” (“Delineating Age” 301). In that sense, an ‘old’ person playing with Legos would contribute to the assumption that the very early and the very late stages of life are comparable in terms of physical abilities as well as mental capacities. According to this reading of the scene, it would still be Berns’ physicality that determines the way his age is constructed. To the audience, at that moment, he appears ‘old’ to the extent that he is unable to remain part of a midlife-sphere and has to return so his social role as a child. Here it becomes clear how physical age determines social roles through cultural imaginaries.

The latter reading of the scene, however, is deemed inappropriate by a voiceover in which Berns explains: “I didn’t put myself in front of you to have you feel bad for me. I put myself in front of you to let you know that you don’t need to feel bad for me because this is how... I want you to get to know me. This is my life and this... progeria is part of it. It’s not a major part of it, but it is part of it” (00:01:49-00:02:10). The audience learns the reason for his rapidly aging body, which explains that the action of playing with Legos is a juxtaposition to Berns’ aging body and not a way of coping with it through therapy. Consequently, in this initial scene, the audience is presented with the struggle of the subcategories of age: On the one hand, Berns would be considered to be ‘old’ through his physical and outward age, represented by the appearance of his arthritis struck hand. On the other hand, he would be considered ‘young’ according to his behavioral age as he plays with children’s toys.

The documentary here emphasizes the otherness *and* the sameness of Berns’ persona. By saying that what is aging in him is aging in everybody, it establishes him as part of a society that is worried by aging demographics and the prospect of decline. In contrast, the documentary encourages its audience to see the differences between Berns’ aging body and his social role as a child and thereby suggests an approach to the story that is not overshadowed by stereotypes surrounding the aging body. In that sense, all cultural connotations belonging to the aging body, such as immobility, decline, or death, are negated by the action of playing with Legos. At the same time, all connotations belonging to the action of playing with Legos, childhood and primarily health, are negated by the aging body. Finally, Berns’ statement again contributes to the normalization of his condition in general. He does not want pity or preferential treatment. He wants to explain his condition so that it can be normalized within society. Ironically, Berns advocates for the absence of what makes his narrative so interesting for this study: He wants his extraordinary age to become ordinary and therefore invisible, as well.

Berns’ behavioral age adds yet another nuance to the image of his age through his description of progeria. He describes the condition as a part of his life, yet not a major one. He actively positions his life in a way that distances him from the overwhelming associations going along with the aging body. His statement

therefore counters all assumptions people could make about his life and his abilities due to his physical age by foregrounding his behavioral age. This works against the cultural imaginary of 'old' age and questions the power the aging body should have in this construct.

By challenging the role physical abilities should have in the construction of the self, Berns' narrative asks its audience to see the value in the aging body. This demand for a value-centered view on the body, connects back to Sally Chivers' demand of, in reference to disability studies, accepting deviating bodies as "different ways of being in the world" which can be "sources of knowledge, satisfaction, creativity, and happiness" (*The Silvering Screen* 9). Accordingly, the field of disability studies, so it could be argued, is one step ahead of aging studies in acknowledging the value and meaning in bodies that deviate from a supposed norm. In the sense of disability studies, the simple act of playing with Legos and being hopeful despite his aging body can be read as an attempt to view the aging body in exactly the way Chivers proposes. Berns' narrative thus challenges Western societies' derogatory assumptions of the aging body precisely by not portraying it as negative but merely as 'there.' Ultimately, to see both binary oppositions of 'young' and 'old' within one individual fosters an understanding of this binary being a mere cultural imaginary and that, in turn, the negative image of the aging body could be redefined along the lines of value and knowledge. To reinforce Berns' initial statement, throughout the film, he is often shown in environments that are generally associated with youth. He appears in class with his friends, talking about homework assignments and projects or, he is shown at a rock concert. Hence, the film underlines that, in everyday life, his physical age is not given the power to majorly interfere with his behavioral age. Conclusively, the cultural connotations of the aging body are objected by his social status as a student. In those instances, the physical state of his body does not seem to be important. It is through this focus that Berns' physical age is undermined whereas his behavioral age is maintained and even enhanced.

As opposed to the images provided in the initial scenes, the film also shows situations where Berns' physical age is placed at the center of attention. A large portion of the documentary deals with his mother, Leslie Gordon, and her quest to find a cure for progeria and, ultimately, a medication that slows down the aging process in all people.<sup>1</sup> To do so, the documentary accompanies Sam Berns through

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1 This is again tied to the assumption that studying extraordinary forms of aging medically might help to gain insight to the general process of aging. It is stated on the HBO homepage, promoting the documentary that "gaining a better understanding of how the disease works could lead to breakthroughs in treating heart disease and aging in the general population" ("Life According to Sam: About"). Researching progeria thus is not only the starting point of my research, it is also used as a promotional tool, toying with societies wish to undo aging and to find eternal youth. This point will be further elaborated on in chapter 7.2.

his required hospital visits, showing the processes of examinations and attempts at treatments. These scenes foreground his physical age. During his treatments, he is separated from his life, which foreshadows the social isolation that the later part of life supposedly brings with itself. About his experiences in the hospital Berns says: "When I'm in the hospital, I'm isolated from friends, I'm isolated from television, I'm isolated from my home, I'm isolated from my cats. It's like I lose all of the things that make me me, except for progeria" (00:52:48-00:53:34). What Berns describes here is disengagement as his aging body forces him to spend time in the hospital where he has to deal with nothing but the signs of 'old' age. Hence, the progeria body has a similar effect on Berns as the aging body is supposed to have on the elderly. It is in these moments in the hospital that physical age becomes Berns' defining feature and he is, like the elderly population, associated with decline. He thus falls victim to disengagement, yet a disengagement that is specific to time and place. The audience knows that his state of isolation is only prevalent in the specific context he finds himself in. Here, again, it becomes obvious how certain social and cultural contexts influence the significance of a given category of difference. That is, the context of the hospital enhances the prevalence of Berns' physical age, while withdrawing the determining power of his behavioral age which then influences his self-identification: The way Berns feels and identifies in relation to his aged body differs from situations in the hospital to situations in school, for instance.

The encouragement to rethink assumptions about the aging body becomes even more prominent in a later scene when Berns tries out for his school's marching band (01:06:30-01:10:50, 01:28:47-01:30:48). Here again his youthful behavior, the wish to play in a marching band and the drive to do everything humanly possible to achieve that goal, is juxtaposed to the restrictions he faces due to his physical condition in terms of being able to march in sync with the band and play or even carry the drum. Nevertheless, he is determined to make his dream come true and his parents find a way to design a lighter harness for the drum, giving him the chance to participate in the band. In that instance, his performance shows that it is not necessarily the body itself that keeps individuals from participating in certain activities. Rather, it is the way these activities are designed within a given society. In pursuing this argument, Chivers suggests that "[a] person in a wheelchair may not be able to navigate stairs, but that is a challenge only in a society that builds stairs, rather than ramps" (*From Old Woman* xxix). Accordingly, being physically weaker than others is only a problem for Berns because he lives in a society that builds heavy harnesses in the first place. His efforts and the efforts made on his behalf are attempts to encourage society to become more inclusive for all kinds of different bodies, including the 'old' one. Further, it becomes obvious that, in certain environments, Berns' aging body is not a victim to disengagement from society of which he is an active part. Conversely, the narrative of Sam Berns shows that the aging body alone cannot keep him from participating in social activities.

The lesson the documentary teaches its audience is that there are means to keep the negative connotations of the aging body and their impacts on later life at bay. This possibility should be transferable to the elderly as well. Since it is possible for a child with progeria to overcome the boundaries of the aged body, why should the elderly not be able to do the same if they want to?

It is, in that connection, only because the documentary shows Berns' life in that particular light, that the call for a treatment for progeria is legitimate. His quest for meaning and happiness emphasizes the need to help children with progeria. This medical argument then brings back the notion of 'old' age as a disease and it is important to bear in mind that, in this special case, 'old' physical age truly is a disease. In that connection, the documentary can be read in two different ways. Besides the positive aspects of suggesting that the aging body can lose the burden of its cultural connotations through the emphasis of other aspects in life, it also implies that an attempt to 'cure' aging would be an idea to be welcomed. Accordingly, the flipside of the narrative reveals that focusing on Berns' behavioral age, serves the purpose of supporting his request for a longer life. In other words, only because he is acting and feeling 'young,' the spectator is inclined to believe that it is necessary to search for a cure in the first place. This, in turn, shows that, drawing on one category of difference while withdrawing another, when done deliberately, always serves a purpose, in this case the purpose of promoting the efforts to find a cure for progeria and ultimately, to prolong the human lifespan.

Despite these very different approaches to the documentary, the narrative works toward a deeper understanding of the aging body and implies that there is a possibility for meaning and value in life, even towards the end of it. This is why it is important to reveal that Berns' behavioral age is used in many instances to overwrite his physical age. In this very context then, Berns serves as an example for a progress narrative. Sam Berns fights decline by highlighting his possibilities. Additionally, his example shows that aging is not a matter of black and white. Having an aged body might restrict a person from engaging in certain activities but it does not restrict that person from being happy and leading a meaningful (later) life. Looking at the construction of age(ing) in *Life According to Sam* shows that for him, physical age is not the determining factor of his life, unless he is put into situations that make him focus on that subcategory of his age. Further, comparing the way extraordinary age is constructed in this narrative to accounts of centenarians already touches upon a major issue: physical 'old' age being accepted as part one's life may only be possible if the other two age categories are not considered to be 'old.' 'Old' people, on the other hand, can be regarded as being constantly put into situations in which their physical age is foregrounded.

## 7.2 Progeria and Clinical Trials

Despite the general depiction of Berns' life and, connected to that, his extraordinary age, one main theme in *Life According to Sam* is the search for a cure—or at least a treatment—for progeria. The documentary does not only touch upon the general endeavor of the PRF but also on the early trials for a treatment. Thereby, it becomes a medical narrative, exploring the ethical realms of drug trials, as well as the human stories behind them. In that connection, this narrative becomes a piece that strongly advocates for a human rights cause. Here, it can be related back to Schaffer and Smith's assumption that life narratives concerning ethical issues and justice implicitly aim to provoke a response in their audience (3). Telling the story of a clinical trial may evoke the wish within the audience that the treatment will be marketed, as long as the process is depicted as just and ethical. Berns' parents, who founded the PRF and are both pediatricians use the film as a platform to elaborate on their quest for a cure. The emphasis on the similarities between the progeria body and the aging body serve as an appropriation for their research as it promises to help the aging population in general. The documentary only depicts the early stages of human trials, culminating in a publication of the results and therefore the starting point of the FDA's review process.<sup>2</sup> While this is a tremendous breakthrough, the documentary does not point towards the lengthy process that will have to follow to get the treatment approved for general use. The audience is inclined to think that the fight has been won, yet the drug depicted in the documentary has only been approved in November 2020, seven years after the documentary's release, as the first ever treatment for progeria ("First Treatment").

The drug trial only comes into being because Berns' parents are pediatricians and have the means to do the research themselves. The documentary touches upon their personal fight to find a cure that was initiated with Berns' diagnosis. Although both parents are physicians themselves, their quest for a diagnosis remains a substantial struggle. This common trope within progeria narratives is incorporated into a family history of how Leslie Gordon and Scott Berns met and had their first and only child. While the story of the couple's first meeting is told by Sam, the story of his diagnosis is narrated by his parents:

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2 The FDA clinical trial process is divided into four phases, the first testing for toxicity and dosage in healthy people, the second testing for side effects and first signs of efficiency, the third testing for efficacy, and the fourth testing for safety and efficiency. Each stage is accompanied by a review process (US Department of Health and Human Services).



**Leslie Gordon:** When Sam was born, to us he looked normal but even when we look back, we can see something that just wasn't right. And we went to our pediatrician, and we kept saying something's wrong, something's wrong.

**Scott Berns:** He wasn't really gaining weight over that first year and a half and we attributed that initially to the fact that he didn't eat as much, he spit up and babies spit up, right? And I noticed there were things about his skin that I would think 'this is a little bit different around his stomach and what's that all about?' And we are both physicians, so I was like 'oh, maybe we're being too sensitive about noticing some of these things.'

**Leslie Gordon:** It just came from my soul, like 'something is going on here.' It was incredibly frustrating. Finally, a brilliant friend and colleague of ours came up with this idea that Sam might have progeria. (00:28:25-00:29:30)

The point I would like to make is connected to narrative structure. Sam Berns elaborates on his parent's relationship, while they tell the story of his diagnosis. This intertwines both storylines as the parents speak about the son and the son speaks about the parents. Although they are interviewed individually, they are presented as an inextricably linked unity. Moreover, Sam's story becomes the story of his parents and vice versa. This specifically shows how progeria is not the issue of an individual but of an entire family: Sam's illness is also his parent's illness.

Besides stressing the communal aspect of progeria, the story of Sam's diagnosis reflects a certain helplessness on part of his parents. Although, or especially because they are physicians, they are not sure what to make of their son's symptoms. They are even hesitant in their narration, indicating that they are unsure whether they always handled things right. Scott Berns, for instance, needs to reassure himself that it is normal for babies to spit up, thus justifying why he did not initially worry about his son. Ultimately, this story tells a gradual process of figuring out that there is something wrong in the first place and then defining what exactly this might be. Sam's diagnosis is not a sudden metagnosis for his parents but a slow break in identity and the grappling with the notion of something being wrong after all. This slow process from regarding their child as perfect, to sensing an illness, to finally diagnosing Sam with progeria is depicted as a pivotal procedure in the family's identity from average to a family of fighters. It is this change in identity that leads to Gordon's quest to find a cure for progeria, initiating the clinical trial.

In addition to presenting the diagnoses or gradual, extended metagnosis of Sam Berns and his family, the narrative dedicates a substantial amount of time to the depiction of the progeria drug trial. Depicting both these processes provides hope, not only for the children represented but also for every person who may be scared of the aging process. According to Daniel Callahan, "[h]ope drives good medical care, for the physician and the patient" and nowadays, "[h]ope also drives the war against aging and disease" (91). He thus indicates that hope is the motor

that initiates improvement in health care and medical practice. In the case of Berns' parents, this is certainly the case, as their hope to save their son sparks their interest in the research they are doing. Hence, hope is needed to strive for a better health and to fight conditions even if they seem hopeless. For Callahan, it is this promotion of hope that makes "[t]he present period . . . a revolt against death itself" (90). This quote also speaks to the human hybris of thinking all diseases ultimately will be curable. Furthermore, as 'old' age is considered a 'waiting room' for death, revolting against death itself is inherently also a revolt against the aging process.

The clinical trial is depicted from two different perspectives: the perspective of Leslie Gordon, Sam Berns' mother, as the researcher in charge of the trial and that of Sam Berns as a patient within trial. Gordon's perspective is a rather scientific one. She is the educator, explaining to the audience how the disease affects the human body, as well as how clinical trials in general and the progeria trial in particular work. She narrates the trial, explains how the experimental drug is supposed to work, and what medical and ethical risks are part of the endeavor. Thereby, she also becomes an advocate for progeria research in general. The documentary shows that, in order to make this research happen it needs a person educated within the field of medicine who is willing to dedicate all her time and energy into this project. With the low number of progeria cases worldwide, it is not surprising that this person had not been found before Gordon started her endeavor which, of course, was also a highly personal one. This is also connected to a lack of money. As becomes clear in the documentary, clinical trials for conditions only affecting a few people lack funding. Therefore, the constant reference to progeria and its relatability to all aging processes becomes all the more important, as it makes Gordon's research beneficial for the entire human population. Nonetheless, Gordon stresses her role as an advocate for children with progeria. When elaborating on her research and its benefits for humanity, she states that "the aging fields will take this and run with it, but my job, my passion, is to stick with these kids" (00:24:53-00:25:03). While she uncovered a biological mechanism that may benefit aging research tremendously, she sees herself as responsible to prioritize progeria research above else. Gordon thus becomes the personified hope for children with progeria and their families.

Although Gordon has a personal connection to the trial, in reference to it, she is depicted as researcher and an advocate for the progeria community first and Sam Berns' mother second. Therefore, her perspective is a professional one. Berns, on the other hand is depicted as the patient whose personal connection is inevitable, as the trial directly affects his body and his identity. Whereas his mother's account is also always connected to the fact that she is trying to save her son, her narrative focuses much more on the scientific and ethical aspects of the trial. Sam Berns' account, on the other hand, is nothing but personal. As mentioned above, he feels that being at the hospital deprives him of everything that defines his identity (00:52:48-00:53:34). The clinical trial and the connected examinations are thus an unwelcome

reminder of his condition that is otherwise in the background of his life. Nevertheless, he understands the importance of the trial and the fact that the time he spends at the hospital may ultimately lead to him improving. His hope, which is ultimately a representative for the hope of all children with progeria and their families and friends, is rewarded when he gets the results of his trial and the physician states that his “numbers are phenomenal” (01:24:25). Consequently, all the hardship and the temporary loss of identity have been worth it because, according to the trial results, the treatment is working. Berns then overcomes his role as a mere patient and becomes a character who has successfully fought his condition.

Connected to this, Berns points out that due to the trial he now understands his condition better and thus can move forward: “I feel like now progeria is more known, I know more about it genetically. So, it’s less of an embodiment now. It used to be that thing that prevents me from doing all this stuff that causes other kids to die that causes everybody to be stressed and now, you know, it’s a protein that is abnormal but we can subtract ourselves” (01:29:40–01:30:11). Once he knows about the biology of his condition, it is less of a burden in his life. This implies that society needs education, not only in terms of renegotiation cultural imaginaries but also in terms of understanding the biology of a condition to move forward. His identity is no longer tied to the unknown or a vague metaphor. Rather, for him, knowing more about his condition has the power to normalize it. Hence, things that are considered to be ‘different’ need to be normalized through knowledge. This does not mean that we do not acknowledge that there are differences, rather, that we accept that there is no norm. If understanding the biology of his condition helps Berns to move on, it may also help people to move on if they find out more about the biology of aging. I would argue, however, that it is not only the biology that we need knowledge of in order to overcome, but that we need cultural knowledge of these issues as well. In that sense, this documentary provides knowledge about the biology and knowledge about life with this condition, hence, normalizing both. This line of argument then points to a general need for more diverse representations in all areas of life in order to provide cultural knowledge of lives that deviate from a supposed norm.

Besides focusing on the implications of the trial with regard to the aging body as well as illness and medicine in general, the documentary reinforces the transnationality of illness and, implicitly, also of aging. When it comes to the depiction of the trial it quickly becomes obvious that there are families from all over the world participating. Hence, children with progeria and their families from all over the world come to Boston in order to be part of the trial and to share the hope provided by Leslie Gordon. Consequently, she is not only helping her son, but she is also helping the world. While she is thus not primarily depicted as a mother to Sam Berns in the context of the trial, she is presented as a motherly figure to a community of children with progeria. This does not only emphasize the sense of a common

effort towards finding a cure but also enforces a universality of the condition: This can happen to anyone. Gordon then uses her mother role in order to emphasize this universality not only of the disease but also of her motherly role within it. She explains that “[p]eople will say things like ‘I don’t know if I could do this’ and my answer to them is ‘yes, you could’” (00:04:33–00:04:38). She thus tones her own achievements down and humbly implies that everyone would act the way she does in her situation. In combination with the transnationality of the clinical trial, she becomes an icon of a community who is not only humble but a pioneer in research, leading the entire world to success. In the U.S., this speaks to a national self-image of progress and American exceptionalism. Staging researchers from the U.S. as the leaders who will solve a worldwide problem adds to the inclusion of the audience into the general ideology of the narrative. In that sense, Gordon becomes a pioneer, leading an expedition into unknown territory of progeria, a role model for the rest of the world to look up to. In that sense, her role echoes U.S. cultural tropes of Winthrop’s “city upon a hill” (121) with all eyes and hopes on her and her trial. Through emphasizing the trial as a transnational endeavor with United States researchers at the front lines, the documentary thus evokes a sense of national pride connected to it.

Moreover, depicting progeria as a global phenomenon evokes a sense of community that counters the often-depicted narrative of illness and individual overcoming. Rather, Leslie Gordon advocates a communal approach to the disease, which in turn forms an infrastructure of support. At the same time, the connection between progeria and aging in general suggests the question whether, if progeria is addressed as a worldwide issue, aging should be as well. If so, one could argue that not only the medical but also the social and cultural aspects of age(ing) need to be regarded from a transnational angle in order to understand the cultural processes surrounding it.

Discussing the progeria clinical trial shows how *Life According to Sam* is not only a narrative of Sam Berns’ life but also a narrative of a human rights claim for a treatment of a terminal disease. Thereby, the trial narrative shows how disease and treatment influence a person’s identity, as it forces people to become patients and exist in environments where the condition is the center of their entire being. It puts Leslie Gordon in the position of an U.S. American hero who sets out to save the world, implying that she will not only save children with progeria but the aging population as well. This narrative implicitly plays on a general fear of dying within its audience, supporting the claim for the necessity of a cure for progeria all the more prominent. Nonetheless, the depiction of the trial offers perspectives on approaches to the aged body in general: There is a need for diverse narratives of all bodies, including age(ing) bodies, in order to establish a cultural imagery that defies notions of a powerful norm. According to this understanding, all bodies

would be considered 'different' as all experiences are unique, ultimately challenging norms in general.

### 7.3 A Philosophy for a Happy Life: Sam Berns' TED Talk

Besides being part of the documentary about his own life, at the age of 17 Berns gave a TED talk called "My Philosophy for a Happy Life." Whereas documentary and TED talk were published in the same year, listening to Berns' elaborations in the talk indicates that filming the documentary took place or at least had begun four years prior ("My Philosophy" 09:45). This talk does not only present the opportunity for a now matured Sam Berns to share his perspective on life, but also it can be read as a marketing strategy in order to promote the documentary. Both aspects will be discussed in further detail in chapter 7.4 concerning voice, agency, and perspective in *Life According to Sam*, as well as in Berns' TED talk. This current chapter focuses on the contents of this talk and the implications it makes toward Berns' aging process as well as the aging process in general. By looking at Berns' philosophy and reading it against the grain his inclusiveness of the broader population becomes the excluding factor for 'old' people. The TED talk here implies is that there is a line between 'old' people and the rest of the world that has nothing to do with the aging body.

The core message of Berns' TED talk clearly is that, deep down, he is just like any other person on this planet, thus countering imaginaries presented by narratives like "Living with Progeria." This message is incorporated into his philosophy for a happy life which is based on four elements:

- Be OK with what you ultimately can't do because there's so much that you CAN do
- Surround yourself with people you want to be around
- Keep moving forward
- Never miss a party if you can help it (12:16)

All these aspects relate to the everyday life of the audience but are intensified by the fact that the narrator has a terminal disease. Moreover, reading this advice against the grain offers many insights into the way the aged body is regarded within society and at the same time provides a criticism of the very same.

The first point on Berns' list refers to a focus on a person's ability in acceptance of restrictions. Reading it with Berns' condition in mind, this becomes a powerful statement which is reinforced by telling the story of him joining his school's marching band, mentioned above. Berns makes clear that progeria is something he does not constantly think about. In other words: He is not his condition. This

is directly connected to scenes in the documentary where he states that progeria does not define him. In that instance, the messages given within the documentary and within the TED talk align: Berns' physical age does not restrict him from many things he wants to do. However, he specifies that "sometimes [he] need[s] to find a different way to do something" (Berns 04:05). In other words, there are some things that he needs to work hard for or find compromises. Connected to that, by telling the story of the things he *can* do once he has put some effort into them, he sparks a thought process: Are there not things in life for every person that they cannot do or have to work harder for than others? For instance, not everybody can join a marching band. This does not have to be due to physical restrictions but may be due to a lack of musicality. If I cannot play the trumpet, I will not be successful in trying out for playing trumpet in a band, and if I do not have the rhythm and the hearing for it, I may have a very difficult time to learn playing the trumpet. These different talents and abilities in every individual are often taken for granted. Only if there is a label such as disease, disability, or 'old' age assigned to this inability, it becomes a stigma. If Berns indicates over and over again that his body and therefore his physical age is not connected to his identity, this same claim can be made for 'old' people. Yet, popular narratives suggest the opposite: Only an able, 'young' body can be an acceptable body. Here, again, the narrative highlights what Chivers has argued: For disabled bodies there are advocates claiming their value, while for the aged body society seems to be stuck with the assumption that every value is deeply connected to physical ability.

The second element of Berns' philosophy is rather straight forward: If you surround yourself with the people you love, life is always better. Again, this advice is applicable to most lives and therefore underlines Berns' sameness to the rest of society. However, connecting this point to narratives previously discussed shows that choosing the people you surround yourself with, often is a privilege. Looking at Aldéa Pellerin-Cormier, George Dawson, and Adalia Rose shows that sometimes people are not able to choose the people to surround themselves with. This may be due to their institutionalized age or their physical age or, more broadly, due to their interdependence. All three individuals cannot go anywhere by themselves and have to rely on others. Especially in the case of the centenarians, most friends and siblings have passed away. Family members have their own lives and people *they* want to surround themselves with. Irrespective of physical ability, there seem to be more possibilities for 'young' people to mingle with peers. This points to the general assumption that the need for social activity is thought to be absent in 'old' people. What reading Berns' philosophy against the grain shows then, is that the very privilege of deciding who you want to spent time with, is a privilege of the 'young' and able-bodied.

The third point on his list clearly refers to the future and something to look forward to. Although 'old' age (especially 'old' physical age) in public imaginary is

inextricably linked to a lack of future, Berns defies this notion. Instead of imagining himself in a ‘waiting room’ of the ‘old,’ he emphasizes the need to look ahead. This need for a sense of a future appeared to be crucial within centenarian narratives as well and, according to Lindberg and Marshal is a key element of successful aging. This sense of future thus emphasizes the sense of successful impairment surrounding Sam Berns. Moreover, by sticking to a future oriented mindset, Berns does what experts suggest for a meaningful life (cf. Edmondson). However, this also raises the question whether his orientation towards the future is socially more acceptable because of his ‘young’ institutionalized and behavioral age. Especially the latter could be a significant factor within this part of his philosophy: It may be considered ‘young’ behavior to orient oneself toward the future, making it sanctionable for those considered to be ‘old’ to do the same.

The fourth and last point of Berns’ philosophy may seem rather trivial, but it is the only one that cannot be read in terms of age or ability. Rather, Berns gives advice here that only applies to extrovert people who like to party, drawing an implicit line of inclusion—not with age but with character. Nonetheless, as this TED talk shows, the emphasis on physical age and physical restrictions is deeply connected to institutionalized age. Physical decline is thus a bigger issue with the increase of the number of years a person has lived. This is intensified by social structures and support systems that support ‘young’ people not only in the four points Berns deems necessary for a happy life but in general. Ultimately, in his TED talk Berns reinforces his sameness to the general population, thereby often excluding ‘old’ people.

#### **7.4 Sam Berns as Commodity: Agency and Perspective in *Life According to Sam***

The previous chapters have shown that agency can have many forms and connotations. Macklemore’s grandmother, Helen, is merely shown and staged by her grandson and does not get to speak at all, which presents as rather straight forward denial of agency in terms of voice. Aldéa Pellerin-Cormier gets to speak but she is only given the chance to talk about questions that have been asked by the producers who therefore set the tone and the direction of the narrative. George Dawson’s case is the most complex one, since agency is intertwined with authorship and co-authorship, as these issues are directly addressed within the narrative itself as well as the surrounding para-texts. In Adalia Rose’s story, it especially was a form of medical agency that seems to be taken from her, as she is denied her own voice or even knowledge in important matters for purposes of protection. The Vandeweert sibling’s agency is tied to institutionalized age and gender, providing 21-year-old Michiel with power over the narrative, while keeping 12-year-old Amber

in the background. Thus far, all examples discussed have shown that agency often lies with the middle-aged, depriving the audience of narratives of aging—and in this case specifically of extraordinary aging—of the unadulterated voice of the extraordinarily aged. Hence, the audiences of the various narratives do not get to see stories that are untinged by the expectations of others; that is, untinged by the imaginations and causes of a middle-aged understanding of the aging process. Here, middle age becomes the cultural norm, the one in power, glossing over individuals' perspectives and romanticizing their stories.

While in *Life According to Sam* similar mechanisms apply, there are several points that this narrative specifically adds to the discussion of agency in terms of age(ing). Berns' story is as carefully orchestrated by different agents as the narratives previously discussed. However, these mechanisms do not solely aim at showing that a great life is possible despite or because of extraordinary age. Rather the purpose is finding a treatment for an illness. I am thus interested in the way Sam Berns' agency appears to be different because of this different aim of his narrative. In what way is Berns commodified not as a paragon of aging, but as a paragon of patients or paragon of illness and what is his own take regarding these mechanisms? In order to discuss these questions, I will not only consult the documentary itself but also refer back to Berns' TED talk, which is included in the extras of the documentary's DVD. I will read the message he aims to convey within his TED talk against the message of the documentary as a whole.

As mentioned in the introduction of this chapter, *Life According to Sam* was produced for the pay TV channel HBO and promotes the medical search for a treatment for progeria. When it comes to agency within the narrative, there are several components at stake. First of all, HBO wants to produce contents that make people subscribe to their channel. The documentary therefore needs to speak to a wide audience and tell a story that they can relate to which the narrative achieves in various ways. As Schaffer and Smith argue, “[p]ublishing houses . . . convert stories of suffering and survival into commodified experiences for general audiences with diverse desires and also for an increasing number of niche audiences interested in particular kinds of suffering” (23). HBO, as the institution that would be considered the publishing house in the world of television, needs to make sure Berns' experience is understandable and relatable for all kinds of audiences. This is achieved through the focus on the universality of the aging process, since, no matter where you are from and what (sub)culture you belong to, you age. Therefore, as mentioned above, in the first few minutes of the documentary, on-screen lettering appears, informing the audience that “[w]hat is aging in Sam, is aging in all of us” (00:03:07). This is a recurring theme throughout all progeria narratives, as relatability presents one of the core needs for generating in audience in the first place. At the same time, this relatability in terms of the aging process ties in with the second aim of the documentary: to generate support for a cure. This second



aim is the main goal of the PRF, an organization in need of funding in order to continue their research. Here, the interests align perfectly, as reinforcing the need for a cure works through the constant emphasis on the universality of the aging process.

The second mechanism to achieve relatability with the audience is the use of common tropes of U.S. American culture and history.<sup>3</sup> As mentioned above, Leslie Gordon is presented as a pioneer in research, leading the whole world into a better future. Moreover, like George Dawson's narrative, one way to regard Sam Berns' story is as an example of the American Dream. Berns is portrayed as a perfect student, helping his classmates with difficult tasks (00:06:19-00:06:45) and receiving numerous awards for outstanding achievements at his middle school graduation (01:01:04-01:02:05). Furthermore, he is presented with a very positive attitude towards life which triggers ideas of overcoming all odds and achieving the previously considered impossible which are mechanisms inherent to the myth of the American Dream. This connection is intensified when Berns tries out for his High School's marching band. Although it looks like he cannot join the band initially, he, or much rather his mother, finds a solution of having a custom-made harness so Berns can join the band after all. These instances of overcoming are ever present in the narrative and are deeply connected to an U.S. American cultural understanding. This, in turn, makes Berns' narrative a typical US American one and, therefore, highly relatable to an U.S. American audience. These two major currents within the narrative contribute to making this documentary a sellable one.

The second important agent within this narrative is the PRF, represented by Berns' mother, and the search for a treatment and, inextricably linked to that, support from society, especially financially, as the PRF is also funded by private donations ("Give"). It surely is no coincidence that besides Berns' TED talk, the only other extra material provided on the DVD is an introduction to the PRF. As mentioned above, the relatability of progeria to 'old' age is certainly a strand of the narrative that is emphasized by their take as well.

Consequently, two very strong agents have their stakes in what *Life According to Sam* should look like in order to be sellable. These elaborations are not meant to excoriate either HBO as a network or the PRF and their search for the cure. Especially the latter fulfills a highly important purpose that is surely worthy of support. Rather, this discussion aims at showing the powerful mechanisms behind the narrative in order to shed light on the means and aims of its production. Ultimately, looking at these two corporate aims of the documentary, inevitably leads to the question what role and what voice Sam Berns has in his own story. Within

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3 The documentary is available worldwide. Yet, HBO as a pay TV channel is foremost consumable in North America. Hence, it is specifically important to speak to this target audience and include them by the use of common cultural tropes.

the documentary, Sam gets to speak for himself, yet, he is presumably also bound to the questions he is asked. He appears knowledgeable about his condition and what it entails for his life and the life of his friends. Although his mother is very protective of him, he does not appear to live within a protective bubble. Rather, he goes to a public school, plays in his school's band, and visits concerts with his father. The interview mechanisms, as opposed to Rose's narrative, are very different. For instance, Berns is interviewed on his own, without his parents and gets to speak about his condition and his take on life. While he potentially has no say in the images that are broadcasted or the way the narrative unfolds, at least he is not censored in a way that denies him his own take on his story completely.

Whereas the documentary consists of the aims of others, Berns' TED talk may give a clearer picture of his own take on life and his condition. Looking at the TED talk as a comparative narrative is fruitful for the discussion of agency for two main reasons: First, the TED talk can be assumed to be closer to the core message that Berns wants to bring across and is thus closer to what appears important for the extraordinarily aged individual. This message, with all its implications read with and against the grain have been thoroughly discussed in the previous chapter. Here, it is important to add that Berns' TED talk, in his core message, aims at a similar message as the PRF: We are all the same and we are all in this together. This may also be, because Berns himself holds stakes in the quest for a cure for progeria. He is the person in this narrative who will profit from a drug that may prolong his life. However, while the PRF's message focuses on the medical standpoint, specifically including 'old' people, reminding its audience that everybody ages, the TED talk brings this to a social level. Berns indicates that every individual can have a happy and meaningful life by following his simple steps. Second, in his TED talk, Berns retells one of the storylines included in the documentary: the narrative of him wanting to join the marching band. Hence, this talk offers the unique opportunity to compare the focus of the two narratives and thus discuss their respective aim and intention.

The second point presents to be the most interesting one in terms of narrative agency and perspective because the marching band story provides the same storyline, told from two different angles. In the documentary, it is mostly Berns' mother who advocates with his teacher to give him a chance in the band. There are scenes in which the mother is cooped up in the teacher's office with him discussing options. Berns, at the same time is shown trying out for the band and coming to his mother with his problems. While trying out for the band, his mother is close by and when he is unable to carry the harness with the drum, he approaches her right away:

**Sam Berns:** I can't march with this thing on.

**Leslie Gordon:** [Removing the harness and the drum from his shoulders] Do the motions without the drum. Go ahead. (01:06:08-01:06:16)

While Gordon is depicted as a person who solves problems quickly and efficiently, Berns, in this very scene, is not an active agent but a helpless child. This depiction is of course necessary in order to stage his mother as *the* mother figure for all, as the heroine who will ultimately save all children with progeria.

In Berns' own narrative, however, the wording he uses puts himself into the position of the fighter. For instance, he explains that when it comes to playing in the drum line, "nothing was going to stop [him] from playing snare drum with the marching band" (01:20-01:21). In the original, he obviously uses "me" which indicates his own willingness and drive to overcome his problems. This is a stark contrast to the way the narrative is framed within the documentary as it shifts the focus away from Berns' support system onto him. This shift provides him with agency. At the same time, in the TED talk, one could argue, Berns undermines the importance care and support play in the fulfillment of his philosophy. However, he does not claim full credit for overcoming his snare drum problem, as he states "my family and I worked with an engineer to design a snare drum harness that would be lighter and easier for me to carry" (01:26-01:32), thus acknowledging that this was a common effort. Neither the TED talk, nor the documentary specify whose initiative it was to approach an engineer. However, untangling the mechanisms behind this is only of secondary importance as comparing the two narratives shows that there is a break between the depicted agency when it comes to the marching band storyline. In connection to that, the importance of this part of the story for Berns becomes much clearer in the TED talk. It is not only presented as his personal achievement, but also the very first thing he tells his audience—a story of success, proving that his philosophy works. In the documentary, on the other hand, the marching band storyline is just one of many stories told about Berns' life.

Besides these two main points of the inquiry in this subchapter, I would like to briefly turn my discussion towards the issue of Berns' own perspective within the TED talk, as opposed to the documentary. In addition to reusing the marching band story, Berns references one other part of the documentary: the pivotal moment where, through a better understanding of the medicine, he gains a better sense of his life and can move forward and away from progeria. This scene, that has been discussed in chapter 7.3, is cut into Berns' talk, including his own statements from the documentary. Consequently, Berns shows that there are instances where his own narrative aligns completely with what is shown in the documentary. In other instances, he specifically refers to a shift of perspective through time. He explains "[a]bout four years ago, HBO began to film a documentary about my family and me called *Life According to Sam*. That was a pretty great experience, but it

was also four years ago. And, like anyone my views on many things have changed, and hopefully matured” (09:36-9:50). In this moment, Berns speaks about his career choices, but this statement can also be read as a more general disclaimer for anything he may say in his TED talk that comes across differently within the documentary: His character has evolved; he sees things differently than four years ago. With these intertextual references he also points to the question of perspective: He says that some of his opinions on life have changed since he is now seventeen. Thus, the way life in general and age(ing) in particular are regarded is also always influenced by the life stage we are currently in. Berns hence confirms Gullette’s claim that a life narrative is always dependent on the moment it was written in. In other words: The same story, told by the same person may differ if it is told four years apart. Crucially, Berns uses the term *matured* which is often connected to a person’s behavior. What he describes in this instance is a change of perspective or attitude with increasing behavioral age. He implies that his perspective now should be given more merit, as his behavioral age has increased, and maturity has historically been tied to agency (cf. Field).

In conclusion, Berns does not use the increased agency he gains through his TED talk, to commodify himself or his condition but his attitude towards life which presents a significant difference to the documentary. However, many of the things Berns points to in his TED talk are also present within the documentary. Some of them may be framed slightly different, like the marching band storyline, while others are very much the same, as for instance the conclusion that Berns is not defined by his condition. However, it is also very clear that the focus of the documentary is a rather different one. Here, the interests of the PRF and HBO seem much more prevalent than in Berns’ own narrative. Ultimately, the documentary’s title is then somewhat deceptive as it claims to portray what life is like according to Sam Berns. Rather, it portrays what life with progeria is like according to the PRF, as well as how this life is best marketed for an HBO audience.

## 7.5 Framing Extraordinary Age(ing) in *Life According to Sam*

Using the HBO documentary *Life According to Sam* as a case in point, this chapter has shown how progeria as an extraordinary form of aging can contribute to the discussion of age as a cultural imaginary, the social roles tied to it, as well as the influence of the biological aspects of the aging process. As Sam Berns’ condition puts him between being ‘old’ and being ‘young’ by juxtaposing physical and behavioral age, his story shows how age itself is a fluid construct that is constantly redefined through the environments it is situated in. Ultimately, it is Berns’ behavioral age, made possible through supporters who are willing to work against the constraints in his environment, which determines how he is perceived and perceives himself

through his age. The situations in which his body and his physical age are the center of attention are restricted to the hospital, where he is isolated and fragile which leads to an understanding of the aging body as a challenge—which it undoubtedly is for everybody experiencing it—but one that does not have to be the defining aspect of a person's life.

Berns does not 'act his (physical) age' (cf. Laz) in his philosophy, thereby undermining the social emphasis that is put on this very aspect of the aging process. However, looking at his narrative also shows that the most arbitrary subcategory of age—institutionalized age—has a lot of power over the way age in general is determined, as it overwrites cultural imaginaries of the aging body. Thus, Sam Berns is not seen as an 'old' person even though the documentary constantly points to his physical age. Ultimately, the narrative remains an illness narrative, as well as a coming-of-age narrative, rather than one of 'old' age in any sense.

Progeria, and Sam Berns at the same time, are then commodified through otherness *and* sameness. The complex structures that this narrative is set in depict progeria as a communal disease, emphasizing a common aim not only for children with progeria but for everyone. It thus echoes claims of disability studies scholars to move away from depicting disability as an individual experience. At the same time, Berns is portrayed as an average U.S. American teenager and his story becomes an archetypical U.S. American story of success. Thereby, he is not only part of the progeria community but also of the (trans)national community in general. Especially his TED talk points to the sameness of his life and his alignment to a social norm. Interestingly, there is also a sense of the ordinary within Sam Berns' narrative, not only communicating his belonging within society but also a universality of the condition or illness as a whole. Illness, according to this narrative, can happen to anyone and is therefore specifically not an individual but a communal issue.

## 8 Framing Progeria in an (Auto)Biography: Hayley Okines' *Old Before My Time*

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*Old Before My Time: Hayley Okines' Life with Progeria*, the (auto)biography of Hayley Okines and her mother Kerry Okines<sup>1</sup> is another example of a collaborative narrative of extraordinary age(ing). Like George Dawson's (auto)biography, Hayley and Kerry's story is co-authored: They hired author Alison Stokes to support them in writing this book. The product is a full-length (auto)biography that covers the period from Hayley's birth until around her fourteenth birthday. The mode of production deviates in some ways from the narratives I have discussed so far. While the issue of co-authorship is as prominent as in my discussion of *Life is So Good!*, the makeup of *Old Before My Time* differs largely, as it provides clear indications of who the author of a certain chapter is, with Alison Stokes being entirely absent throughout the narrative. Yet, it is again fruitful to examine who tells the story and how it is influenced by perspective.

Out of all the progeria narratives looked at in this study, Hayley's story is the one making the most direct connections between her condition and centenarianism. The title of the book's blurb is "The Extraordinary Life of a 100-Year-Old Teenager," which deliberately draws a link between the two phenomena. This connection emphasizes how concepts of extreme 'youth' and extreme 'old' age seem to clash and converge in Hayley's story. As such, the concept of the aging body stands in stark contrast to the concept of the 'young' mind. Hence, the connection between progeria and 'old' age in general, and centenarians in particular, is very strong within this narrative. Therefore, the aging body, disability, and disease are much more intertwined in this account than in the narratives discussed in previous chapters. In that sense, Hayley's story becomes the piece of the puzzle which undeniably links the narratives of children with progeria to the narratives of centenarians.

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1 To avoid confusion, I will refer to both by their first name or full name. Furthermore, I will refer to the narrative as "Hayley's story" in various instances, as she can be considered the protagonist of the book. I am, however, aware, that this is a narrative that was also largely written by and about Kerry Okines and her experiences.

Besides these implications about the aging process, looking at Hayley's narrative offers yet another take on the importance of perspective when it comes to telling a story. Since there are not many children with progeria, it is no surprise that Hayley would have met the Vandeweert siblings, as well as Sam Berns. While Hayley is absent from their narratives, *Old Before My Time* elaborates on their friendships and the way those connections help in order to come to terms with the condition, yet again stressing the importance of community. Furthermore, Hayley Okines was part of the progeria drug trials in Boston, led by Leslie Gordon and depicted in *Life According to Sam*. While the documentary presents the narrative from a more scientific point of view, this (auto)biography approaches the trial from the perspectives of lay people and patients.<sup>2</sup> In that sense, Hayley's story provides the perspective of a family that had been unaware of the existence of progeria and their journey to acquire knowledge about the condition. By providing insight into the process of diagnosis and the importance of a supportive community, this book is a prime example of how narratives have the power to alter the world and how representations or the lack thereof can be a harmful factor to a life.

In this chapter, I am interested in three main issues that are connected to the previous discussions within this study. First, *Old Before My Time* offers another point of inquiry on life writing, aging, and perspective, as the chapters in the book are divided up between Hayley and Kerry, often dealing with the same plot but shaping the story from their individual perspectives. Much like Sam Berns' TED talk, this gives a frame of reference for how a story is told by different individuals and how Hayley's experience may differ from the one that is presented by her mother. That is, the narrative provides insight into how Hayley's extraordinary age is described by herself as her own lived experience versus how it is described by others. This topic will be an underlying issue of the entire chapter: the individual perspectives of Hayley and Kerry, as they wind through discussions of the aging process and the progeria drug trials.

Second, I discuss the intertextual references between *Old Before My Time* and other narratives that I have mentioned in the previous chapters. Here, I am especially interested in the way these relations are used to provide a better understanding of progeria as a condition itself but also about different perspectives concerning medical issues. Furthermore, I will look at the importance of community with regard to progeria and connect that to a general need of community in people of all ages.

Third, I look at the way narratives of progeria as an extraordinary form of age(ing) can highlight cultural assumptions that go along with the aging process.

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2 The patient perspective in *Life According to Sam* is covered by Sam Berns himself; however, his mother's elaborations as the scientist on the case interfuse the sole patient narrative.

Here, I first look at the story of Hayley's diagnosis and its implications for the perception of the disease. I then discuss how life with progeria is presented and how this may disrupt assumptions about age(ing) in general. These assumptions do not only include age(ing) per se but also questions of care and agency throughout the life-course. The narrative provides many fruitful thoughts on the connection of the aging body, illness, and disability, as well as the juxtaposition of age categories in general.

Hayley Okines' condition is used to decenter normative concepts of age(ing) by drawing attention to a teenage girl with a prematurely aged body. In that regard, Hayley's narrative provides many direct references to normative expectations of 'old' age. Therefore, I am looking at the way these connections in particular frame the aging body and the depiction of extraordinary age as well as how the reading of Hayley's age relates to the construction of age(ing) in a normative sense. As her age becomes a media phenomenon, she does not only present a narrative that can raise awareness for her disease, she also challenges demeaning connotations of the aging body. It is precisely because Hayley Okines is 'old before her time' that her narrative allows us to explore topics of 'old' age and decline, showing an alternative way of dealing with 'old' age, individually and publicly. In its depiction of the aging body, the narrative features many themes detected within the examples looked at previously. The unique opportunity here is that we are dealing with a full length (auto)biography that also outlines how assumptions about age(ing) in general evolve through the reading of Hayley's extraordinary aging process.

## 8.1 *Old Before My Time* and Narrative Structure

As the chapter on George Dawson and his co-author Richard Glaubman showed, co-authored (auto)biographies present a minefield when it comes to questions of voice and agency. While the audience of documentaries at least gets to hear a person speak for themselves—however scripted this speech act may be—readers of written texts must rely on the “ethics of life writing” being honored (cf. Couser; Eakin). *Old Before My Time* presents yet another curiosity when it comes to authorship: the narration is divided between Hayley Okines and her mother Kerry. Although the title of the book suggests that the reader gets to experience a narrative about and by Hayley, a closer look at the authors as well as inside the book reveals that this is a story about and by Hayley *and* Kerry, told mostly by Kerry. In this subchapter, I am thus interested in the narrative structure of the (auto)biography. I will discuss the way the co-author Alison Stokes is presented as well as how the voices of Hayley and Kerry differ. Ultimately, I will argue that the narrative provided here appears to honor the “ethics of life writing” and captures two distinct voices that offer two distinct perspectives on life with progeria: Hayley's and Kerry's. Stokes,



on the other hand, appears to be absent from the narrative. This subchapter then serves as the foundation of the discussion of the two perspectives presented within the narrative.

In the case of George Dawson and Richard Glaubman, the role of the co-author was often questionable because of the way Glaubman presented himself within the media and within the narrative, establishing himself as the main agent. Alison Stokes, the co-author of *Old Before My Time*, on the other hand, appears to be very absent from the public. A Google search reveals that she has co-authored many books (including two more with Hayley), however, she does not overshadow any of the people she has worked with; she does not even seem to have her own website. Thus, there is no apparent self-promotion through the people she works with. Furthermore, she does not appear in the book's acknowledgements at all. What is even more curious is that she is not mentioned on the cover whereas Hayley and Kerry are clearly presented as the authors. Her only appearance is on the title page, where the authors of the narratives are listed as "Hayley and Kerry Okines with Alison Stokes." Stokes' name is set apart from the other two authors not only by the word "with" but also through several line breaks. Stokes is thus depicted as apart from the two main authors with linguistic and typographic measures. It becomes very clear that this is not an equal partnership, but that Stokes played a smaller role in the production of this book than Hayley and Kerry.

This impression becomes even stronger when looking inside the book. Unlike *Life is So Good!*, *Old Before My Time* does not include acknowledgements from the co-author. In fact, Stokes is not even mentioned in the acknowledgements provided by either Hayley or Kerry. Therefore, it is very easy to overlook the fact that Stokes was even involved in the process. This representation could indicate a glossing over Stokes' part in the production of the narrative. It seems possible that the authors want to make the reader believe that her voice and her perspective are absent from the narrative. Yet, looking at the way Stokes presents herself online as well as the fact that she does not appear within the book itself—and thus does not seem to have become an important part of the Okines' life—at least leaves the feeling that she really acted as a 'ghost' in the background, capturing the voices of the individuals whose narrative she is helping to bring across.

While it is of course still possible that Stokes understood how to cover her traces better than Glaubman did, it is obvious that the reader gets to hear two distinct voices in the narrative, which they can assume to be Hayley's and Kerry's. I will argue throughout the chapter that the two present different perspectives and perpetuate different cultural imaginaries of progeria, the aging body, and its biology. What is important here is that the structure of the narrative makes it very clear whether the reader hears Hayley's or Kerry's voice, as the author is indicated in each chapter heading. Hayley's sentences also tend to be shorter than Kerry's and have a simpler grammatical structure. This, of course, indicates that her 'young' age

leads to a less eloquent expression.<sup>3</sup> Besides the difference in syntax, there is also a difference in length, as well as the fact that for the first part of the narrative—until Hayley's first day of primary school to be precise—the reader only gets Kerry's perspective. This, of course, makes sense, as Hayley would not be able to remember the first years of her life and even as she starts to remember, these first memories are less detailed and therefore shorter.

As I will outline in the following subchapters, the reader is hence presented with two very distinct approaches to progeria, focusing on the aging body, cultural imaginaries of age(ing) and disease, social roles connected to them, as well as on care and treatment. Especially the latter becomes interesting because the reader is introduced to the perspective of the caretaker *and* the person who they take care of. The following subchapters will thus elaborate on the way progeria is presented within the (auto)biography and will deal with age(ing), care, and medical implications while bearing in mind the two different perspectives as they are presented in the narrative.

## 8.2 Intertextual References and Conflicting Narratives: Clinical Trials and Connections to Other Children with Progeria

Kerry Okines presents herself and her family at the core of the progeria community. Accordingly, several families who have been subject to the previous chapters are mentioned within *Old Before My Time*. Thereby, the narrative not only offers another perspective on these families but also another take on the progeria clinical trials. While Leslie Gordon in *Life According to Sam* represents the scientific perspective, Kerry and Hayley are medical lay people and approach this trial from a different angle. I will therefore use this subchapter to briefly describe the most prominent intertextual references to Michiel and Amber Vandeweert, as well as Sam Berns, highlighting differences in narrative perspective. I will then analyze the extent to which Hayley's and Kerry's patient and lay person narratives differ from the medical narrative provided by Leslie Gordon. Thereby, I will focus on the way progeria is renegotiated through different perspectives and individuals.

The Okines are close to the Vandeweerts because of regional proximity as both families live in Europe. Because of the proximity, they frequently travel together to clinical trials and support each other. Like many other families living with progeria, the Vandeweerts and the Okines met at a progeria reunion. These annual meet-

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3 If we assume that Stokes was more involved in the process than the publication would like us to believe, this would indicate that there is an underlying assumption concerning language skills and age. At the very least, having the teenager speak in a 'simpler' language will not surprise the audience and make the narrative more 'authentic.'

ings for children with progeria and their families were established by the Sunshine Foundation, a foundation dedicated to grant wishes to terminally ill children (“Sunshine Foundation”). According to Kerry, she played an important role in the Vandeweerts’ life, claiming that they “had us to thank for the diagnosis of progeria in their son” (39). Kerry reports that the Vandeweerts saw a documentary about Hayley, recognizing her symptoms as the same as Michiel’s. In the “Living with Progeria” clip about the Vandeweerts, on the other hand, Wim Vandeweert attributes the diagnosis to Michiel’s doctor at a day care center (00:09:55-00:09:59). While there is no way of saying who is telling any kind of truth, Kerry positions herself in the center of the world of progeria while Wim Vandeweert does not acknowledge such a position. To him, the connectedness of a progeria community seems to only play a minor role whereas, in his regard, professional medical personnel provides assistance when it comes to required guidance concerning progeria-related questions.

The two narratives differ in another crucial point. Both tell the story of the Vandeweerts’ struggle in deciding to have another child. In “Living with Progeria,” Wim explains that they were debating having a second child and ultimately decided in favor of it since the probability of having two children with progeria is extremely low (00:10:05-00:10:35). Kerry, on the other hand, elaborates on the issue in a much more detailed manner:

Fearing the condition was hereditary, Wim had a vasectomy but after seeing Hayley’s first documentary alarm bells rang. Looking at Hayley was looking at their own child, they told us. The premature aging, the hair loss, the stiff joints, were all identical. Armed with this information, they went back to their doctor and asked if it could be progeria . . . Wim had his vasectomy removed and in 2005, they had a baby girl, Amber. (39)

Besides being even more specific in how the Vandeweerts allegedly came to the progeria diagnosis because of the Okines, this statement provides a lot of extremely private information that is not given in the Vandeweerts’ section in “Living with Progeria.” Wim Vandeweert thus becomes a “vulnerable subject,” according to Couser, whose medical history is told by others. Additionally, this discrepancy shows how different narratives can provide very different readings of the same story: The outlook on potentially having another child with progeria, according to *Old Before My Time*, seems so grave that the Vandeweerts opted for the drastic action of a vasectomy, eradicating any chance of procreation. In “Living with Progeria,” on the other hand, Wim speaks about the low chances of the condition occurring twice in the same family, thus indicating that they did not wish for another child with progeria but clarifying that they were very willing to take the chance. Leaving out the vasectomy narrative makes life with progeria seem more acceptable because they would have welcomed another child even if there was a chance that this child might also have the disease. Ultimately, what

this comparison shows is that the two narratives place different emphases on the topic of progeria. Since it is important for the sensationalizing narrative of “Living with Progeria” to present heroes who overcome an implied gruesome fate, the narrative cannot present such a hero as someone who would try to avoid this very fate repeating itself. *Old Before My Time*, on the other hand, focuses more on the hardships of the disease and the struggle to overcome them by establishing a working community of support. For a narrative of overcoming, painting the fate as drastically as possible makes sense because in this case the process of overcoming is the more prominent aspect.

The issue of conflicting narratives is also prevalent in the Okines' relationship to Sam Berns and his family, simply because the Okines are not even mentioned in *Life According to Sam* whereas *Old Before My Time* portrays the families as being very close. Not only are Leslie Gordon and Scott Berns described as a vital source of information shortly after Hayley's diagnosis (34), they are also close enough to take a trip to Disney World together, where Kerry hears about the upcoming progeria drug trial from Leslie Gordon herself (109). Leslie Gordon is portrayed as a central figure in the progeria community in both narratives, however, in *Old Before My Time* her expertise remains largely in the medical realm. In *Life According to Sam* this medical expertise is certainly highlighted as well, yet Leslie is also framed as a pillar of social support for children with progeria and their families. Featuring Kerry, as another figure who supposedly acts in this very center, would not support this framework. Furthermore, Hayley, as one of the most prominent children with progeria at the time, may have simply taken the stage and the focus may have shifted to her. This, again, is only speculation about the producers' choices, however, the decision to exclude the Okines from Sam Berns' documentary makes narrative sense, as their appearance would have shifted the narrative framework tremendously.

The clinical trials in Boston, as well as the tests prior to them and the aftermath, form a large intertextual reference to *Life According to Sam*. The Okines' perspective differs, as it offers the perception of lay people and patients within a clinical trial. This perspective is laced with naïve assumptions and hopes about the trial, a state that Kerry is somewhat aware of: “Our once naïve notion that a pill could combat Hayley's condition now seemed to be more real. But the question remained—would it arrive in Hayley's life time?” (110). This shows that Kerry, as a lay person, is not well-versed in questions of drug trials and their time frames, usually taking many years to arrive at completion. However, she has learned to be cautious when it comes to hope. This caution decreases throughout the narrative as Kerry begins referring to the treatment as the “new miracle drug” (119), showing that the more involved she gets with the trial, the more she allows herself to hope for a working and approved treatment within Hayley's lifetime. Again hope becomes the driving factor. In this case not to facilitate the trial but to take part in it and thereby risking potential side effects for Hayley. Hope, as the driving factor for good medical prac-

tice (cf. Callahan) here becomes a driving factor for taking medical risks. Without hope, Kerry would not have risked enrolling her daughter within the clinical trial, a trial that only exists because Leslie Gordon has the hope that progeria can be cured. Hope hence works on both sides: There needs to be hope driving those who do the research and hope in those who make themselves available for the testing process.

A sense of urgency is prevalent in the discussion on whether to join the trial in the first place. Despite the tentative hope expressed about a potential drug, Kerry initially remains skeptical and discusses her concerns with her husband:

‘Are we doing the right thing, taking part in this trial?’ I asked Mark. ‘This drug has never been tested on humans before. We don’t know if it will work or if it will cause more damage.’ We had been warned about the possible side-effects which ranged from mild nausea on one end of the scale to possible death at the other end. ‘Without it the prognosis is not good, so we have no choice, really,’ Mark said. He was right. Without the drug we were four years away from the dreaded life expectancy age of thirteen. (113)

Here, the narrative is brought right into the middle of a biomedical ethics debate (cf. Beauchamp and Childress). Kerry must weigh the potential benefits against the potential dangers or, in ethical terms, decide if the principle of nonmaleficence—do no harm—can still be regarded as met in these trials. Ultimately, Kerry and her husband Mark justify their decision to have Hayley join the trial by referring to the limited time they fear having left: “She’s getting older . . . It’s a risk I’m willing to take” (114). While this makes her weighing of the situation comprehensible to the reader, it also shows that she is neglecting one aspect of biomedical ethics completely: patient autonomy. As Kerry speaks in singular form, it becomes clear that she sees this decision as hers to make and not as Hayley’s. Patient autonomy, a concept that formulates the requirement of informed consent of a patient for a procedure to be ethical, is therefore completely overlooked. The question of autonomy, however, is made more complex through Hayley’s institutionalized age. Through her function as legal guardian, Kerry is legally allowed to make medical decisions for her daughter. Moreover, it raises the question of whether a person at about nine years old can even make a fully informed decision in the first place. Here, the presentation of the ethics of medical decision-making echoes the narrative of the protective infrastructure surrounding Adalia Rose. She, like Hayley, is excluded from any form of decision-making concerning her own body. Interestingly, in neither of the narratives this conundrum is addressed as such, implying that the question of informed consent is no issue at all.

Within this entanglement, it becomes even more important to also look at Hayley’s perspective on the issue. The way she approaches the trials is clearly influenced by the way her parents frame it for her. Her chapter about the early stages of the trial is called “I’m gonna grow hair” (116), indicating not only that, from her point

of view, her outward appearance is the most troublesome part of having progeria, but also that she expects the experimental treatment to be highly sufficient and powerful. This attitude is echoed within the chapter when Hayley describes how her mother approached her about the possible treatment. She explains that Kerry “said that the tablets were very special and hadn’t been given to many children with progeria before and I would be one of the first. That made me feel really special” (116). While there is no secret about the experimental nature of the medication, this fact does not register with Hayley. For an adult, taking a pill that nobody has ever taken before may be a red flag. Hayley, however, unknowing about drug testing procedures or even the potential dangers of untested medication, cannot be expected to make this connection. Still, she is aware of some tensions concerning the trial on her parents’ end. She elaborates:

At first I didn’t really think too much about what the trial meant because I was still quite little. I just thought let’s go for it. Mum and Dad were worrying about it and making all the decisions. But I was too little to understand. Some days I could tell they were really worried. They didn’t have to say anything, but I could tell. When I saw they were scared I wondered why they were so worried. What’s the worst thing it could do? I could get really poorly. The best thing that could happen would be if I was just like a normal kid. (117)

Here, Hayley herself refers to her ‘young’ age and claims that she did not understand the complex questions surrounding the trial. This justifies Kerry’s decision-making, yet Hayley’s elaborations also show that she understands that something is amiss. Thus, although it may seem a lot to fathom for a child, Hayley’s side of the story shows that she is affected by the debate no matter what, which makes a case for at least trying to include her in the process. Hayley also makes clear that she trusts her parents to make all the decisions without questioning their authority. The immense trust that children generally put into their parents in turn gives the parents immense power, which they use and thus eradicate any chance for autonomy on Hayley’s part. Reading Hayley’s perspective on the drug trial then presents the reader with implications on the ethics of consent. In that connection, it presents to be an advocate for a narrative form of ethics. Laurie Zoloth and Rita Charon argue that “narrative texts and methods can inform the decisions faced in the world of biomedical ethics” (22). Following this argument, reading *Old Before My Time* against the grain implies that children, who may be assumed to be oblivious of the finer nuances of a biomedical decision, are confronted with overarching tensions and are therefore entitled to at least be part of the conversation.

No matter the ethical dilemma leading up to it, Hayley is signed up for the drug trial. Once the trial begins, the Okines collectively struggle through the science of it. As opposed to Leslie Gordon, they are not medical experts but “[t]he doctors did their best to explain . . . how they expected the new drugs to work” (121). As lay

people, they have to trust the physicians who become mediators between science and the family. Consequently, Kerry continues to elaborate on how “a ‘bar’ molecule called a ‘farnesyl group’ attached itself to the progerin protein and stopped the cell from working properly. The FTIs would act as a barrier, stopping the progerin from damaging the cells and slowing down the ageing characteristics of progeria” (121). With the knowledge provided by the physicians, Kerry becomes an expert and a mediator for her audience. She journeys from being the person in need of guidance to the person providing guidance. In instances like this, the narrative becomes a story about Kerry’s own journey and her empowerment as much as it is about Hayley’s life. In this specific scene, Kerry even rises above the mere patient status and becomes a bearer of medical knowledge herself.

Hayley, unlike Sam Berns, does not focus on the treatment before and during the drug trial; instead, she tells her readers about the outcome of it. This, of course, may be connected to the purpose of the respective narrative and therefore the questions the producers or co-author asked. Like his mother, Sam Berns focuses on the medical part of the trial, meaning the portion of it that takes place in the hospital. Hayley, on the other hand, barely mentions her stay at the hospital other than stating her pride about being the only child who is able to lay still in an MRI for 45 minutes (117). Hayley describes her role as a patient almost as if it were a game she is winning, which ultimately shows her general ambition to perform well in life. Moreover, she continues to elaborate on how the drug personally affects her. After having a few side effects, she starts to “feel like [she] was getting stronger” and to be able to run around at school with her peers (127). While this hints at a reduced physical age, it also presents a narrative different from Sam Berns’, which gives a very medical elaboration on how the treatment improved the symptoms of progeria. This echoes the different foci of the narratives: while *Life According to Sam* focuses on the medical, *Old Before My Time* focuses on the social. Hence, Hayley does not see her social role as affected by the framework of the hospital. While she explains her dislike for needles and procedures, she never describes herself as disengaged because of her patient status. Rather, she incorporates trips to the hospital into her everyday life by regarding them as a game.

Lastly, Hayley mentions another very unmedical outcome of the drug trial. She muses: “It’s like the drugs are making my mum stronger too. She used to be so sad and sometimes used to cry when she was talking about me to her friends and Nana. But now I have been taking the tablets she has stopped crying, and that’s good. I think she knows there’s hope” (128). According to Hayley, the drug not only has a medical effect but a social one as well. Kerry and Hayley can now live a more hopeful life which generally increases in quality. In summary, the drug trial narrative in *Old Before My Time* is in many aspects fundamentally different from the one provided in *Life According to Sam*, as it focuses on the social rather than the medical and on the improvements rather than the negative sides of the patient status.

Nonetheless, there are also essential similarities, for instance in the negotiations about ethics and the special entanglements presented when dealing with children. Moreover, both narratives provide a sort of empowerment of the people involved in the process, as both sources describe the trial as a small victory over the disease.

Intertextuality here serves as a point of reference for the way all narratives are orchestrated. Furthermore, it shows how diverse perspectives offer diverse stories, thereby pointing to the importance of listening to a variety of stories and perspectives in order to present a well-rounded picture. Interestingly, however, these narratives, although they present different perspectives on certain details, all somewhat align when it comes to the depiction of progeria and the general need to help the children.

### 8.3 In Search for the Illness: Hayley's Diagnosis

The perspective on progeria is bound to differ between Kerry and Hayley not only because Hayley is the one actually experiencing it, but also because she does not know herself in any other way. As mentioned before, the Vandeweerts' and Sam Berns' parents had a difficult time coming to terms with the progeria diagnosis of their children. In *Old Before My Time* Kerry describes this experience in detail and lays out the journey from believing to have given birth to a healthy child, through the process of diagnosis, and finally to coping with the disease. The steps she describes are again comparable to Kübler-Ross' stages of grief—denial, anger, bargaining, depression acceptance. Kerry starts by describing the helplessness of thinking that there is something wrong with her child and that nobody can help or even believe her. In the chapter "Am I Being Paranoid?" (8-14), she describes how "Hayley was not gaining weight" (8) or states "I noticed she had two little lumps either side of her belly button" (9). Ironically, much of Kerry's concern stems from the fact that Hayley does not grow like other children. In that instance, her physical age appears to be younger than her institutionalized age, simply because she is small. In terms of size, this stays with Hayley throughout her life. She is always considered 'small for her age.' Yet, as the narrative continues, her body is still constantly connected to 'old' age. Here it becomes clear, that it is always the problematic part of age that is highlighted. Age is made visible through one fraction of a subcategory deviating from normative assumptions and thus becomes the only part visible to the onlooker.

Despite Kerry's concerns, doctors do not take her seriously and tell her that there was "nothing to worry about" (9). Referring back to the narrative of diagnosis in *Life According to Sam* suggests that it is not necessarily Kerry's status as a lay person that intensifies her struggles, as Berns' parents, although pediatricians, faced similar encounters. While Kerry is very much aware and willing to deal with the



situation, the medical system presents to be in denial. Through relentless efforts and countless visits to doctors, the Okines get a tentative diagnosis: “We think Hayley may have a rare genetic condition called Hutchinson-Gilford Progeria . . . We can’t be certain at this stage . . . Be very careful what you read about progeria. Not everything on the internet is factual” (11-12). Generally, this premature diagnosis is described as evoking relief, as it finally provides an answer to all the questions. However, it also bears problems, as in this 1990s setting not everyone is well-versed in or has the means to conducting an internet research. Furthermore, progeria awareness was very low at that time, as is also obvious when looking at Kerry’s odyssey of a diagnosis. Thus, the physician initiates a period of worry and attempts at research on the internet. This struggle for finding a diagnosis in the first place then uncovers what Couser calls the “unequal distribution of power between doctor and patient in medical discourse” (*Recovering* 19). In this very instance, the physician has the power of knowledge but refuses to share this knowledge with the patient. Rather, they encourage the patient to seek knowledge for themselves.

Besides being left alone with the diagnosis, Kerry is also left alone to come to terms with the fact that her daughter has a terminal disease. She ponders the question of killing Hayley and committing suicide. Kerry thus skips several stages of grief and instantly arrives at depression. Ultimately, it remains her own task to find help among other parents of children with progeria. Her struggles then point to two things: The first, rather practical aspect is that the healthcare system does not seem to be equipped to provide fruitful assistance when it comes to rare conditions and it remains up to the affected people themselves to find help and come to terms with their diagnosis. The second, more theoretical aspect is connected to Danielle Spencer’s argument about metagnosis: a shift in identity concerning one’s own health or the health of a loved one may have painful consequences and needs to be monitored.

Moreover, Kerry’s initial reaction to Hayley’s diagnosis shows what the absence of hope can do to a human being. As Kerry is convinced that Hayley will have a short life full of suffering, she does not see a point in making her live this life. While this attitude changes throughout the narrative, it becomes clear that something to hold on to is crucial in order to process traumatic information. Furthermore, Kerry’s behavior indicates that the unknown leads to hopelessness and despair. Relating to this, Mark, Hayley’s father, states that “knowledge is power” (18). This goes along the lines of what Sam Berns says about understanding himself better after learning more about his illness. This is, in turn, applicable to the process of aging itself, which remains a mystery to normative agers until they experience it. Although everybody knows that aging and ‘old’ age exists, nobody knows what it is like for an individual to actually age until they have done so. Although there are media representations of ‘old’ age, they largely lack diversity and tell a story of decline as soon as the body is not hyper-functional anymore. This turns the unknown into something

that is even scarier, as there is no hope for a positive outcome whatsoever. As Kerry has to learn throughout Hayley's life that life with progeria is certainly worth living, every aging person has to learn for themselves that life does not become worthless once a certain threshold is crossed.

Hayley, in contrast, never specifically speaks about having progeria in connection with her short life expectancy or even regarding the things she cannot do. Progeria is just a part of her life and nothing she necessarily needs to come to terms with. For her, the most important thing seems to be the absence of hair, the most distinct indicator of her condition. The chapter in which she speaks about the clinical trial for a progeria drug is titled "I'm Gonna Grow Hair" (116) and deals with the fact that she, too, will soon look like her peers. This focus on appearance suggests that it is not her self-image that she wants to change through the drug trial but the way she is perceived by others. While her condition may make age highly visible to the outside world, it does not do the same for Hayley. She does not regard her condition as something that makes her age faster, instead her focus is on the way her appearance is not in line with normative assumptions. Other than that, progeria is just a part of who she is, as also argued by Sam Berns in *Life According to Sam*. The condition is thus nothing she grows into and that is therefore unknown. Rather, she grows up with it and is never surprised by a diagnosis or by things she suddenly can or cannot do. In that sense, Hayley's extraordinary age is only extraordinary, or even visible, to the outside world.

#### 8.4 Hayley Okines and the Construction of Extraordinary Age(ing)

In the following subchapter, I will outline how Hayley Okines' (auto)biography is used by Hayley and her mother Kerry to negotiate Hayley's aging process from various angles. Both narrators take a different approach to progeria by emphasizing different aspects of it. While they both try to establish a counter-narrative to the way the aging body is perceived in society, the book shows how difficult it is to escape cultural master narratives of 'old' age, even for those who are socially categorized as children. By looking at their attempts to make sense of Hayley's extraordinary aging process, I will discuss how progeria, which complicates established notions of aging, can make the process of aging visible to a mainstream audience and therefore initiate a thought process concerning age(ing) in modern Western societies.

The extraordinary nature of Hayley Okines' age becomes apparent on the very first page of her (auto)biography. In the prologue to the book, she introduces herself and her condition:

My name is Hayley Okines and people tell me I am special. I have a disease called Hutchinson-Gilford Progeria that makes me age eight times faster than other people. The easiest way to explain it is it's like my body is a hundred years old when I am actually thirteen, but I don't like it when people call me old because I don't feel like I am a hundred years old.

This first comment on herself and her condition is very different from the images of 'old' age we encounter in the media. Instead of seeing her body as a burden, it seems Hayley is told that she is special because she lives with this rare disease. Thus, it becomes clear from the very beginning that she refrains from being put into a role of being pitied. To avoid pity she sets out to explain her condition. Much like Sam Berns starts understanding himself better after grasping the biological realms of progeria, Hayley seems to think that the public will understand her better once they have a basic idea of what progeria is. Moreover, Hayley establishes a direct link to centenarians. That way, she connects her story to a more normative aging process but not to one that would be considered an ordinary one. What progeria then shares with centenarians is a high visibility, despite or particularly because of their 'old' (physical) age. In both cases this visibility translates into a form of sensationalism that these narratives feed from. Connecting the two experiences not only heightens the visibility of Hayley's aging process but also the sensationalism of it. Despite the drawn connection, Hayley also uses this introduction to set herself apart from 'old' age as she goes on to juxtapose her aged body, the body of a centenarian, to her 'young' mind, the mind of a thirteen-year-old girl, stating that despite her body she does not feel 'old.'

Her institutionalized age serves as a justification for her behavioral age. Because she is thirteen, she acts like a thirteen-year-old, no matter the implications of her physical age. In that sense, Hayley Okines presents herself as being situated at two ends of the aging spectrum, meaning that she deliberately plays with the juxtaposition of age categories and elaborates on how she is extraordinary. At the same time, her aging body questions alternative theories of aging that try to lead away from the institutionalized age-centered view. Stephen Katz, for instance, traces a tendency to focus on the functional age of a person, meaning the age of the body. He points out that the aging body "drives the imperative to biologise the aging process apart from chronological aging by coordinating the body's biomarkers" ("From Chronology" 129). Accordingly, focusing on functional age, as opposed to chronological age, moves the aging body back into the foreground and evokes a different set of body-related stereotypes. Hayley Okines' functional age would be, as she points out herself, 100. Yet, she immediately restricts the concept of functional age by pointing out that she does not *feel* 'old.' Thus, neither of the two concepts to measure age can be used to discuss Hayley Okines' narrative. Thereby, as it proves impossible to review age(ing) in terms of chronology or functionality,

we are forced to rethink the discourses of aging. The functions of Hayley's body prove the measurements of institutionalized age an insufficient point of inquiry to the aging process while her attitude towards her body questions the attempt to define age through functionality or physical age. Since Hayley has the body of a centenarian but feels and acts like a teenager, she can be seen as both progressing and declining or as neither of the two.

Because Hayley's condition puts her in between the existing discourses of the aging process, both herself and her mother Kerry struggle to make sense of the extraordinary condition Hayley finds herself. Kerry is the one who primarily ponders on the comparison of the progeria body to the aging body, by attempting to adapt institutionalized age in a way that it fits into the biological framework. For instance, when describing Hayley's friend Maddie, she says: "Maddie was almost three years older than Hayley—or 24 progeria years" (34). This comparison shows that for Kerry the aging body and institutionalized age are inextricably linked. Instead of pondering upon the issue that, when it comes to behavioral age, three years can be a lot of difference for children in terms of interest a general development, Kerry focuses on the difference in physical age. While these thoughts highlight the connection between behavioral age and institutionalized age, for Kerry the focus obviously shifts and the body becomes more important than the mind, reinforcing a narrative of bodily decline as the focal point of 'old' age. Moreover, the emphasis on progeria in comparison to the normative aging process shows that Kerry has been 'aged by culture' and thus holds on to imaginaries that make sense to her. Although she is confronted with a condition that turns age(ing) upside down completely, she needs to think about it within the discourses she knows; that is in terms of discourses that evolve around chronology. Therefore, denaturalizing age is very difficult as we lack the discourse to speak about non normative age(ing) and try to make sense of it within the framework of familiar imaginaries.

This perpetration of a normative approach to age(ing) becomes apparent in Kerry's references to Hayley's body in terms of decline. Kerry worries about Hayley going to school and potentially being injured by simply walking down a crowded hallway. She says that "Hayley already had the body of a 32-year-old. One bump and she could break her arm" (44). Kerry makes a connection to the aged body, which may be somewhat out of place, as the bone structure of a 32-year-old is not necessarily this fragile. It shows that the common explanation—that a child with progeria ages about seven times faster than a normative ager—is oversimplifying the process. If Hayley had the bone structure of a healthy 32-year-old, she would not have to worry about a fractured arm from a mere bump in a school hallway. So at least the bones of a child with progeria seem to be comparable to an elderly normative ager faster than the common explanation of the disease would suggest. Nonetheless, Kerry makes an exaggerated assumption about physical decline by suggesting that the older a person gets, the more fragile they are.

However, although decline is certainly one of the most prominent master narratives of 'old' age, *Old Before My Time* in many instances tries to counter these images. This works precisely through the emphasis on Hayley's body being comparable to an 'old' person, yet at the same time pointing to Hayley's difference from 'old' people. For instance, and quite similar to the process of several immigrant groups in the U.S. who sought the approval of the white dominant society by denouncing African Americans<sup>4</sup>, the Okines' progeria narrative in some instances sets the progeria body apart from the normatively aged body by emphasizing the injustice of the disease. This has the effect that the narrative appeals to the reader by implying that derogatory images of 'old' age are justified, while derogatory images of the progeria body are not. It is especially Hayley's mother Kerry who takes up a rather body-centered perspective and thus struggles to make sense of her daughter's disease at the intersection between 'old' age and disability. She writes: "For seven years Mum had worked at a care home bathing frail elderly people every day so she was used to seeing the paper-thin, easily-bruised skin and over-sized arthritic joints on 90-year-olds. But it was hard to accept on her young granddaughter" (63). Despite the fact that Kerry talks about the similarities of the aged body and the progeria body, she makes an important distinction: It is okay to be frail and unable to bathe oneself at the institutionalized age of 90 whereas these problems are worse for the 'young' granddaughter. The reader here is invited to see the injustice of Hayley's prematurely aged body. While there is no doubt that progeria and especially the shortened life expectancy is a terrible condition, this statement confirms that being regarded as frail, and therefore being defined through one's body in 'old' age is acceptable. This, in turn, highlights the injustice of this physical focus concerning children with progeria. The problem here is not that Kerry points at the fact that her daughter should not have these issues, rather, the terminology she uses is problematic. A discourse of frailty and vulnerability deprives the elderly of agency. Juxtaposing this to Hayley's condition, Kerry appropriates the cultural image of the elderly as helpless and, at the same time, implicates that this kind of imagery should not be appropriate for Hayley. Kerry thus tries to distance her daughter from the elderly by emphasizing her body as a sign of disease, as opposed to the course of nature. The distance Kerry establishes between the progeria body and the aged body is necessary for her because even though the two are very similar, the cultural connotations of age and those of disability and disease are very different (cf. Chivers *The Silvering Screen*).

The intersection between age and disability becomes even clearer by comparing Kerry's statements to Hayley's. Hayley often emphasizes, as she does in the very beginning of her narrative, that she does not feel 'old' and that she does not want

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4 For more detail on the topic cf. Matthew Frye Jacobson, *Roots Too: White Ethnic Revival in Post-Civil Rights America*.

to be regarded as such. Therefore, she promotes the perception of her physical impairments as disability rather than age. Kerry, on the other hand, often specifically uses discourses of the aging body to describe progeria symptoms. She thus ironically uses the exact discourses of 'old' age that she tries to set herself apart from by emphasizing Hayley's 'young' institutionalized age. Kerry describes a scene at the progeria reunion, which is held once a year for children with progeria and their families: "There were 27 of the 40 known cases<sup>5</sup> in the world in that hotel, some were playing around the water, others were too frail to play and sat in their wheelchairs at the water's edge" (33). This discourse of frailty, as mentioned above, is exactly the kind of discourse used to talk about the aged body and it is one that fosters images of decline, vulnerability, and passivity in 'old' age.

Looking at this scene from an aging studies perspective, the wheelchair becomes a sign of immobility and dependence; one that keeps people with an aged body from engaging in the world of those who are able to play at the pool. This binary of those who are still able to play and those who are bound to their wheelchairs serves as a reminder of the binary between successful and failed aging. In this instance, however, it becomes evident that there is a difference in the way the reader regards these children. In contrast to the neoliberal imagery of self-responsibility, it is obvious that these children are living with a genetic disorder that binds them to their wheelchairs and are precisely not responsible for their condition. The master narratives of successful aging, on the other hand, dictate that all disability in 'old' age is self-inflicted. Yet, applying the message of the progeria narrative to the aging process shows that aging itself brings physical impairments that are not self-inflicted. That is, because the physical aging process in children with progeria is accelerates and brings impairment, irrespective of their lifestyles, the stories indicate that a certain degree of impairment in later life is not a failure but mere biology. Looking at the scene from a disability perspective, on the other hand, would give the wheelchair, which a with focus on aging would be considered a sign of decay, opposite connotations. It becomes an enhancement that offers mobility and is thus an asset and not a sign of decay. Being in a wheelchair does not mean a loss of ability but is the material signifier of someone's personal empowerment. It thus becomes clear that, while often linked in public discourse, 'old' age and disability have different connotations, or at least disability and illness seem to mean something different in 'old' age.

Ultimately, Hayley's own description of her aging process is closely related to the lens of disability studies as she tries to negotiate the meaningfulness of her

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5 By 2022 the number of known cases had significantly risen. According to the Progeria Research Foundation, there are 132 known cases of the disease worldwide. The foundation assumes, however, that there are more children who are living with the disease but are not diagnosed ("Meet the Kids")

life despite and through her condition. In connection to the dichotomy between her body and her mind, Hayley explains that “[l]iving with progeria is hard. People treat you like you are a baby. I want to shout at them, ‘I’m not a baby.’ They say I can’t do stuff like run around properly and Mum worries that if I run I will fall over and hurt myself. It’s really annoying” (57). Because her body is ‘old’ the outside world perceives Hayley as helpless. The helplessness ascribed to her ironically makes her feel ‘like a baby.’ Attributing the abilities of ‘young’ age to the elderly is a common practice and refers back to the concept of ‘old’ age as ‘second childhood.’ In Hayley’s special case, the stereotype of the second childhood is incorporated into her actual childhood. Yet, her statement shows that she fights the mechanism of deeming her dependent and helpless because of her body. The statement becomes even stronger because, aside from her body, Hayley is in the phase of becoming a teenager; she is in the stage in which children are supposed to gain more independence. Again, the existing rhetoric of the life-course does not provide concepts for discussing this paradox of aging. This lack of discourse stems from a general lack of discourse concerning ‘old’ age that would refrain from the binary structures of ‘young’ versus ‘old’ or progress versus decline.

Instead of focusing on her aging body, Hayley tries to negotiate her life in terms of knowledge and meaning. In that regard, Stephen Katz points out that “narratives are more than just biographical stories: they are practices that connect the contents of stories and the circumstances of storytelling to the art of rendering lives coherent and meaningful” (*Cultural Aging* 132). In the act of writing about her life, Hayley thus tries to assign meaning to it in order to find her own sources of creativity and happiness. She does so in a twofold manner: First, she emphasizes her relationship with her younger siblings who still rely on her advice as an older sister even though they have stronger bodies (98-100). Thus, she gives her life meaning through the interaction with her family and through the role she takes up within its structures. The second means for Hayley to render her life meaningful is through special activities that let her appreciate her condition in the sense that she would not have gotten to experience most of them, if she was an ‘ordinary’ person. She met her childhood idols Kylie Minogue and Justin Bieber as well as Prince Charles. Further, she got to travel to Disney World and to several progeria meetings in the U.S. Due to all these activities Hayley explains: “I don’t feel jealous of [my sibling’s] health. If I didn’t have progeria, I would not get to do cool stuff and meet really cool people” (100). Similar statements occur throughout her narrative and almost sound like a mantra that gives her a sense of meaning.

Emphasizing her many experiences resembles Jan Baars’ redefinition of time and temporality. He elaborates that “[w]e might arrive at a more rewarding and more meaningful understanding of human time in gerontology if we would also approach time from the perspective of constitutive action, instead of only measuring time chronologically” (“A Triple Temporality” 31). In other words, concepts of

chronological time measurement cannot tell us anything about the meaning of a life. In her lifetime Hayley Okines has written three books, met numerous famous people, and made an impact on the lives of those around her. She has thus experienced a lot more than many people have at a much older institutionalized age. The narrative hence asks its audience to think about what constitutes a meaningful life. Hayley Okines is perfectly capable of taking part in 'constitutive activities' despite her aged body. The logic question then is: Why is it thought to be impossible for the elderly to do the same? Ultimately, measuring a life in experience and not in years, Hayley Okines could be regarded as much older than many other people.

Nevertheless, Hayley does not refer to her body as a meaning giving instance. As opposed to narratives dealing with disability, it seems to be difficult for her to see her body as a source of knowledge. In that sense, the cultural images of the aging body just seem too powerful to reverse, even for a teenage girl. Hayley's mechanism of making life meaningful rather works by overwriting the presence of her aging body through the negotiations of her life as meaningful through her behavior. Through the absence of creating meaning through the body and the emphasis of the need to compensate non normative bodies with other meaning giving practices, the narrative supports an image of the aging body as the ultimate burden. Cultural imaginaries of decline and decay in 'old' age are so strong that it seems impossible for Hayley to redefine her aged body in terms of value and meaning. Nevertheless, her narrative shows, that there are means to take the determining power of the aging body away by putting emphasis on other aspects of her existence.

In contrast to her mother, Hayley seems to be rather concerned with being treated in a way that does not align with her institutionalized age. Whereas Kerry oftentimes reinforces that Hayley has the body of an 'old' person, Hayley on various occasions criticizes being treated 'as a baby.' For instance, when it comes to her toys, she explains: "Now I'm older I don't play in my [play]house anymore because it's for babies" (60). Hence, Hayley focuses on establishing a behavioral age that fits her institutionalized age. This is also why she does not want any special treatment, neither the one that would 'baby' her nor the one that would connect her to 'old' age. When she enters high school, the school wants to provide her with lower desks and special chairs. The former because she is smaller than other children her institutionalized age, the latter because her arthritis-struck joints make it painful for her to sit on a hard surface for a long period of time. However, as Kerry points out "she hated being singled out for special treatment" (131). Hence, Hayley wants to blend in, like every other person, but she is denied doing so because her age is always visible. Furthermore, her own perspective on her aging process shows how privileged normative agers are as they do not have to constantly negotiate their own aging process and simply blend in without effort. 'Acting her age' is therefore



not always an option that Hayley and other children with progeria have and, at any rate, connected to active effort.

In that regard, Hayley actively resists any treatment that could make her stand out as 'different' from her peers, with one exception of being allowed to leave the classroom prior to the other students so that she does not have to walk through the chaotic, crowded halls. This, according to Kerry, is the only situation in which Hayley allows for being treated "differently" (131). The terminology of 'difference' versus blending in appears to be quite important to Hayley as has already been mentioned regarding her outward appearance, specifically her hair. This shows that being referred to as 'born different,' as is the case in the documentary discussed in chapter 6, may not be a desirable label for children with progeria. Hayley actively opposes being considered 'different' on account of her condition, thus fighting the stigma of the 'other' that "Living with Progeria: Born Different" suggests by title alone.

Thinking about Hayley's behavioral age it becomes clear that she very much sticks to normative expectations tied to her institutionalized age. This is shown not only in the fear of being treated in any other way than in accordance with her institutionalized age but also in the way she acts out certain life stages. For instance, she goes through an excessive 'pink phase' or, in another instance, is very interested in using colorful make-up. Such behavior is expected from a girl at a certain age, but it is noteworthy that Hayley lives these stages to the extreme. The same mechanisms are visible in Adalia Rose's narrative as she also performs her late childhood/early adolescence in a very obvious way. In both cases, life stages are overperformed leading to the assumption that the expectancy of a limited life may encourage people to live the time they have to the extreme. Looking at these mechanisms from the angle of the general aging process would suggest that this distinct performance is a subconscious strategy to compensate for the aged body through behavioral age.

This emphasis on behavioral age is also connected to normative assumptions about gender. In this regard, it is noteworthy that both Adalia Rose and Hayley Okines not only perform age in a very overt way, they also perform gender by emphasizing their love for certain colors, attire, and make-up. This very visible gender performance is not a part of Sam Berns' narrative, which begs the question about gender and age(ing) in general and gender and progeria in particular: why does age affect different genders in different ways? The gender and age performance occurring in both "Living with Progeria" and *Old Before My Time* bluntly exposes how much the social requirement for females to look a certain way is internalized from an early institutionalized age onward. It seems to be important to look good or at least not to stand out too much in order to be accepted in society. This is also in line with Hayley's biggest wish of having hair someday since having hair would mean to look more like everyone else. This is comparable to the difference in gender

portrayals of centenarians: there, it was also shown that gender roles seem to be a crucial part of an individual's performance, even at the age of 100.

Looking at *Old Before My Time* in terms of age(ing) ultimately confirms the complexity and the arbitrariness of the concept itself. While Kerry frames Hayley's condition in terms of the aging body, thereby constantly comparing it to a normative aging process, Hayley emphasizes her behavioral age. Again, this shows the difference in perspective and how it affects the narrative of an experience: Children with progeria are framed as children in 'old' people's bodies because it fits public imaginaries while they themselves may define their experiences by completely different means.

### 8.5 The Progeria Community: Illness and Care as a Common Effort

While care is not one of the main topics of *Old Before My Time*, it is always intertwined with the story. The roles are clearly assigned: Kerry is the caretaker of the family and therefore also Hayley's primary care person. Nonetheless, the book advocates for the need of a network of care. This network can then work against the overburdening of one individual in charge, as well as against derogatory stereotypes of institutionalized care. *Old Before My Time* suggests that there needs to be a redefinition of the way we think and speak about care in general. All progeria narratives discussed in this book—and *Old Before My Time* in particular—negotiate the infrastructure necessary to take care of a child with progeria in a way that ensures a good and meaningful life.

Caretaking in *Old Before My Time* is addressed on two overarching levels: the private and the public. The narrative negotiates Kerry's personal network of caretaking as well as public institutions, community events, and medical support. In many instances within the narrative it becomes clear that Kerry, who is not trained to take care of a terminally ill child, is overwhelmed by her new role. She states that "there were no other parents to talk to about it, no support groups of the other sufferers for Hayley to meet. We felt completely alone on the start of a journey that would have no happy ending" (17). This statement emphasizes the helplessness and the hopelessness Kerry had found herself in after the diagnosis. As mentioned above, this feeling leads her to suicidal thoughts, not only because she thinks Hayley's life would not be worth living, but also because she is overwhelmed and lonely in her own situation. This then advocates for a need of communal support within this new situation.

The first supporters she turns to are her parents who become not only important figures in supporting Kerry but also secondary caretakers for Hayley. Kerry writes that her own mother "was like a second mum to Hayley. She was just as protective as me and equally sensitive to the comments and stares of strangers" (63).

Hayley's grandmother is thus not only important as an additional person to help take care of Hayley, there is also a distinct emphasis on the importance of familial relations. Therefore, it is important for Kerry to stress that the grandmother is almost like a real mother to Hayley, indicating the importance of having a reliable backup in case Kerry needs a break. Moreover, this relationship between grandmother, mother, and (grand)daughter shows the importance of a mother figure in the first place. As seen in many of the progeria narratives discussed here, Kerry, as the mother, takes on a vital role in her child's life as she works hard to provide a meaningful life for her daughter. The narrative suggests that there is no better caretaker than the mother which in turn emphasizes the benefit of having another figure just like a mother to assist.

By underlining the importance of a mother figure in caretaking matters, the narrative echoes patriarchal structures, propagating women as primary caretakers because this is what they supposedly do best. Although Hayley's grandfather and father also play a role in supporting the care work, ultimately it is mostly done by the women in the family. Hayley's father is by no means absent or described as a bad father. He supports his family, and in the descriptions of care decisions Kerry often uses the plural 'we,' indicating that he is an active part in every decision. However, the narrative clearly depicts Kerry as Hayley's primary caretaker. These structures are also prevalent in elder care and spark the question whether there should be a renegotiation of care in general and in terms of gender and community in particular. The distribution of the roles in caretaking as depicted in *Old Before My Time* indicates the difficulty for one main caretaker to thrive within their role without support and backup, thus rendering a redefinition of care work on a wider scale all the more important.

Kerry's mother extends her role from a mere backup as Hayley's caretaker to being a caretaker for Kerry herself. This is prevalent, for instance, when she advises Kerry in difficult situations concerning Hayley: "When the all-important question of death reared its head, it was Nanna who saved the day" (64). As Kerry is often unsure about how to deal with delicate situations, she turns to her mother for help and comfort. She, in turn does not only support Kerry when it comes to dealing with Hayley but also in her very own private struggles, for instance when she separates from Hayley's father. Her being there for both Hayley and Kerry as a caretaker is important for the network to function.

Kerry's mother also encourages her to get in touch with a larger support system and convinces her to contact other parents of children with progeria. Especially in the beginning, these conversations with other parents are a lifeline for Kerry. "The turning point in my acceptance of Hayley's progeria came from conversations with other families who had already been through diagnosis and were not only coping, but living full and happy lives" (21). Meeting people who find themselves in the same situation as Kerry and Hayley is a significant aid in overcoming the trauma

of the diagnosis. For Kerry, meeting other families is a 'turning point' from hopelessness to hope. Here, the phrase 'knowledge is power' comes to mind again but not only in the sense that it is important to understand the biology of a condition but also in terms of understanding a way of living with it. In that sense hope is power as well. Kerry needs to see that there are others out there with similar problems and, at the same time, that these people have found a way to deal with those problems. This points to the importance of narratives and representations. Now that there are numerous narratives about progeria, families know right away that they are not alone. These mechanisms hold true for elder care as well. Although in 'old' age people clearly know that others face similar challenges, structures of mutual support among families are often absent and individuals are left to cope on their own. Aging might hence be too normalized to be validated as something to require a larger network of aid, neither for the aged person nor for their families. Ultimately, this lack of communal support can lead to a denial of hope of a happy life in 'old' age. Even if such support exists, media images take their toll on the way age(ing) is regarded in a society, overshadowing positive personal stories. Progeria, on the other hand, at the time of Hayley's diagnosis, was a blank page. At the time there were hardly any images in the media about it, giving Hayley and Kerry among a few others the power to define imaginaries about progeria.

The support of a community of families experiencing life with progeria is extended to the support of the so-called "Sunshine Progeria Reunions." The Sunshine Foundation is an organization that grants wishes to children. In their mission statement they say, "Sunshine Foundation's sole purpose is to answer the dreams of chronically ill, seriously ill, physically challenged and abused children" ("About Us"). Regarding progeria, this mission statement was fulfilled by organizing meetings and flying families from all over the world to the U.S. to spend time together. These meetings did not only include fun and games for the children but also talks and education for the parents. Although the concept sounds fruitful, initially, Kerry is reluctant to go:

I, on the other hand, couldn't imagine anything worse than a hotel full of terminally ill children and their depressed parents crying over their short lifespans and mourning the fact there was no cure . . . it was nothing like I could ever have expected . . . As we got closer to the pool, we could hear the laughter and splashes of dozens of children having fun. (32-33)

It becomes clear that even after having engaged with other families and having seen that they lead meaningful lives, Kerry remains pessimistic about these families being able to transfer this meaning into a group context. It takes the visual and sensual confirmation of being there for her to overcome her own negative idea of what life with progeria looks like. At the reunion, her own imaginaries are finally overshadowed and, thus, redefined by the lives lived in front of her. The redefini-

tion of her imaginaries is emphasized in the title of the chapter dealing with the first progeria reunion: “One Big Happy Family” (32) indicates that the support she gets from these reunions is almost like the support of a family. This in turn shows how closely knit this community is perceived to be. By referring to them as family, Kerry describes the bonds between these people as hardly severable, implying that experiencing progeria together leads to these inseverable bonds.

Over the course of the narrative, Kerry evolves from the profiteer of these bonds to the person who establishes them for other people. When the Sunshine Foundation lacks funds to host another reunion, Kerry starts organizing one herself, thereby transitioning from a person in need of a support system to being the support system. Ultimately, she establishes herself as the head of this ‘one big happy family’ and becomes a support figure for other families. Her role appears to be similar to the role Leslie Gordon plays when it comes to the biology of progeria and medical guidance. Kerry is depicted as the social center of the progeria community whereas Leslie is the medical one.

Besides the institutional support provided through progeria reunions and clinical trials, Kerry expands her private care system through a professional caretaker who is trained to deal with terminally ill children. Jane, Hayley’s palliative care nurse, becomes an important part of Kerry’s and Hayley’s life, not by assisting Hayley with physical challenges but merely by being there for her. Supporting Hayley in this way, Jane becomes an integral part of Kerry’s support system. Kerry describes that “[w]atching Hayley and Jane together gave me confidence. They had a special friendship, as well as patient’s confidentiality. Hayley knew if she passed a secret on to Jane, it was safe. And Jane was able to give us the reassurance we needed about Hayley’s state of mind at a time when I was too emotional to cope alone” (54). Hayley confides in Jane and Kerry knows that Hayley is in good hands when speaking with her. Moreover, Jane gives professional advice to Kerry whenever she feels overwhelmed with navigating difficult subjects. For instance, Jane supports Kerry when Hayley starts asking questions about life, death, and life expectancy (53). Besides assisting Kerry, Jane acts as Hayley’s mental health caretaker, comparable to the physicians looking after Hayley’s physical health. She is her confidant and honors patient confidentiality whereas Hayley’s physicians are required to include the parents of a minor into every process. Thus, when it comes to her body, Hayley is not granted confidentiality. Jane, however, makes sure that she receives it when it comes to her psyche.

Jane’s role between Hayley and Kerry becomes obvious when both authors write about the same plot evolving around Jane in subsequent chapters. When Hayley develops bedsores, Kerry explains that “the therapist suggested a special cushion . . . but that was easier said than done. [Hayley’s] stubbornness turned this into another battle of wills and again I was grateful to Jane who managed to convince her” (55). Kerry is often overwhelmed with Hayley’s strong personality. However, Kerry’s

explanation is lacking the details of how Jane manages to convince her daughter. Hayley, on the other hand, describes the details of Jane's attempts to persuade her to use the cushion: "I don't want you to get sores. It might stop you going swimming and doing other things that you enjoy.' I thought about it. I liked swimming. . . . 'OK, I'll have the cushion,' I said" (59). Here, the process of convincing Hayley is not described as an arduous one. Rather, skill and experience seem to be key in handling situations like this, and maybe someone other than a close family member might be better equipped to approach the subject. Jane thus becomes an integral part within the network of care for both Hayley and Kerry. This also suggests that familial care, while important, cannot be the only kind of care provided. For a well-balanced experience, the parties involved need professional input as well.

An equivalent to the figure of a direct, professional caretaker who is an expert on the issues an individual in need of care may face is often absent from private elder care.<sup>6</sup> 'Old' people are also often confronted with changes in their bodies or minds that may scare them, yet these processes are often discarded as just normal aspects of the aging process, denying people the possibility to voice fears and concerns. Rather, there is a stereotype claiming that 'old' people constantly talk about their physical decline and lack any other subjects. This tendency, which is generally met with annoyance, may well be connected to the fears and uncertainties surrounding physical change and possibly to the absence of an understanding, well-trained person who might listen to these concerns. Rather, care, when it comes to 'old' people, is often restricted to the assistance with everyday chores. Elder care, especially when compared to progeria care, does not seem to be primarily about caring for the person themselves but rather about taking care of the household. While this is, of course, an important aspect of care, it is not the only one. As Hayley's example shows, care also includes a person to confide in and to share problems with.

As the examples above show, a person to confide in may be able to mediate in precarious situations. *Old Before My Time*, however, also points to the importance of listening to the wishes of the person receiving the care. In Hayley's story, this is pointed out when she is about to start high school. Kerry wants to send her to an all-girls school, assuming that "she would have more protection from playground bullies" (130). Being eager to protect her daughter she thinks that this type of environment would be more beneficial to her than others.<sup>7</sup> Hayley, on the other hand,

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6 While there certainly is professional elder care, in Western societies there is also a strong advocacy for caretaking within the family. In these instances, professional input is scarce, explaining an increasing number of self-help books being published on the issue of elder care. (cf. for instance Morris' *How to Care for Aging Parents* or Gross' *A Bitter Sweet Season: Caring for Our Aging Parents—And Ourselves*)

7 In doing so, she also assumes that a person's gender influences their behavior towards peers, implying that boys would be more prone to bullying their fellow students. The narrative is

focuses on the support system of friends that had already helped her through middle school. She remembers the situation: “When I had to choose my big school Mum said ‘Wouldn’t you like to go to an all-girls school?’ I told her I wanted to be with my friends. I asked Erin and Lydia what school they were going to. When they said they were going to Bexhill High I told Mum that that was where I wanted to go. I told her, ‘I want to be with my friends, thank you very much’” (135). This shows that Hayley does not solely rely upon a support system that is specific to progeria to help her cope with her situation. Rather, she wants to grow up as normal as possible, including a regular high school experience. Kerry in turn needs to be aware of what is most beneficial for Hayley and listen to her wishes and needs, ultimately allowing for the regular support system of a teenager to remain in place, giving Hayley space away from her illness. Kerry thus frees her daughter from an over-protective infrastructure and decides that life in the world may be dangerous but not living at all may be worse. Consequently, this scene has two take-home messages: 1. Listening to the person who needs care is crucial for high-quality care. 2. Life needs to be defined by more than the aging body and the things one cannot do. The second message mirrors Sam Berns’ advice on how to live a happy life: one should not let one aspect of life define one’s identity. Yet, remembering theories of decline in ‘old’ age or simply the ‘waiting room’ narrative, emphasizes that once one has passed the threshold of a certain institutionalized age, the focus usually shifts to this one factor and ‘old’ age becomes the defining measure of a life.

In many instances, the narrative not only shows a more wholistic approach to care—presenting caretakers for various aspects in life as well as a support system for Hayley and Kerry—it also redefines notions of caretaking. While popular media often imagines care as a nuisance for all participants, the narrative shows that a deliberate system can be beneficial for all parties. The redefinition functions through the way care is described in the first place but also by following the protagonists’ own process of redefining socially conveyed perceptions of care. For instance, Jane suggests that Hayley could visit a hospice for children as a retreat for herself and her family. Initially, especially Hayley’s father Mark reacts with suspicion toward such a place. According to him “[h]ospices are places where you go to die. I’m not ready for it. Hayley is not ready for it” (70). Thereby, he indicates that he connects an institution such as a hospice with death, a connection that many people also

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full of oversimplified statements like this, indicating that, while Kerry has developed a rather sophisticated mannerism when it comes to the care and empowerment of Hayley, she is not as attuned to other finer social structures such as gender relations or stereotyping per se. Conversely, this goes to show that personal experience is the one thing that can make everyone aware of certain structures and willing to work against them. As not all people can experience everything themselves, narratives are important to see the experience through the eyes of others, therefore developing empathy for their situation and becoming attuned to the structures they find themselves in.

make about care homes for the elderly. Consequently, according to Mark, it is impossible to enjoy a stay at such a place because what benefit can there be to visiting a place full of dying children? Ironically, these thoughts are very close to the initial idea Kerry has about the progeria reunions. On this issue, the roles are reversed. Kerry, who has emerged as a positive, hopeful, and, most importantly, open person has to convince her husband to proceed out of his comfort zone.

Mark's initial worries are nullified as soon as the family arrives at the hospice: "When we saw the other families, Mark's worst fears were dispelled. It wasn't a hospital full of dying children, it was a play centre full of children who loved life and everything it had to offer. Meeting other children made us realise how lucky we were to have Hayley in her relatively normal condition. . . . The one thing all these children had was life and hope" (72). Hence, the family is yet again in need of role models to show them that living with a terminal illness does not have to be defined by the thought of death. Here, the narrative suggests that in order to arrive at Kübler-Ross' stage of acceptance, one needs to be encouraged by role models. Again, however, the description shows the tendency to compare one's life to the life of others and only if there are people who have it presumably worse, it is possible to acknowledge one's own happiness. This reading would indicate that Kerry and her family are not at a point in their lives where they can accept that there are "different forms of being in the world," as argued by Chivers, and that they can all bring joy. Nevertheless, the realization that the prevalent imaginaries about institutions like hospices are often more negative than the places themselves is a valuable lesson for the reader. The take-home message of the narrative is that no matter how gloomy one's expectation of any care facility, it is important to experience these things first-hand with an unbiased approach.

Hayley practices an unbiased approach simply because she does not know what a hospice is. She focuses on the activities she engages in while being there, saying that "[t]he first time we went was really fun. There was a big soft room and arts and crafts room. I liked the soft play room. I could jump around lots more without hurting myself" (77). This goes to show that as long as someone is free from the cultural imaginary of certain places such as hospices or other care facilities, they are more open and instantly able to focus on the positive. In this case, it becomes obvious that the hospice offers certain benefits that no other place would. Ultimately, the narrative urges us to give care facilities the benefit of the doubt and be open-minded about the advantages they may provide for a person in need of care.<sup>8</sup>

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8 I am aware of the occurrence of care home scandals, including abuse and mistreatment. My argument here is not designed to deny these instances. However, I would like to argue that these negative narratives are the prevalent narrative provided about these institutions although many institutions provide good care. This general negativity may lead to a reluctance



This chapter has shown the importance of a system of care, not only for the person who is considered the person in need of care but also for the caretaker. Everyone involved needs a comprehensive system in place, including role models that can provide coping mechanisms in difficult situations. This role model function can also be adopted by narratives about a certain topic, which is why one-sided narratives in any area of life may lead to gloomy assumptions about the topic. Likewise, Kerry's example shows that the absence of a narrative and therefore the absence of any point of reference leads to loneliness and despair. In that sense Kerry and Hayley become role models and a support system for other families dealing with progeria. As I have shown throughout the subchapter, this role model function can also be applied to various other care scenarios, including elder care. In that connection, *Old Before My Time* suggests that open-mindedness, community, and personal experiences can help move away from a gloomy imaginary of care facilities.

## 8.6 *Old Before My Time* and Progeria at the Intersection of the Cultural, Social, and Biological

As age in the case of Hayley Okines becomes a phenomenon, the readers of her books and her blog as well as the audiences of her documentaries are invited to reconsider the aging process along with her as a person. The power of a certain cultural imaginary is shown throughout the narrative in terms of age(ing) but also in terms of disease. On the one hand, it provides insight into an instance where narratives and imaginaries on a certain issue simply do not exist. On the other hand, it shows how much, especially for Kerry, the presumptions of progeria are inextricably linked to age(ing). This then shows how progeria as a former cultural blank page is introduced as its own imaginary through narratives such as *Old Before My Time*, foregrounding a relationship of the disease to age(ing). Hayley herself may frame her condition differently, providing another imaginary, but does not have the narrative agency to do so against the already existing expectations of the aging body.

Hayley's social role as a child is also informed by the cultural imaginary of the aged body. Yet, her self-identification and behavioral age work as a counterbalance to images of decline. Kerry is much more inclined to adapt her daughter's role in society to the disease or to her aged body. Hayley, like Sam Berns, rather emphasizes her being part of the norm. Instead of adapting her social role to her aging body, she is more inclined to adapt to cultural imaginaries of gender roles. The biology of aging thus influences especially Kerry's cultural perception, whereas

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to even consider the benefits of a care facility. This emphasizes the importance of narratives which show that these expectations are not met in most care facilities.

Hayley defies notions of decline and refuses to disengage from society because of her body. Ironically, although Hayley's experience is much more defined by biology than by a normative aging process, she puts less emphasis on the very same. Rather, Hayley Okines' self-definition in terms of age proves to be multi-faceted. Despite her physical signs of 'old' age, she does not regard herself as 'old' and she works very hard to avoid stigmatization for her aging body. She purposefully steps out of the 'waiting room' of the aged and into the spotlight of the public discourse, which gives her audience the opportunity to think of impairments that come with the aging body as a biological fact that does not have to limit the worth of a person's life. Here, the narrative again echoes a successful impairment paradigm: On the one hand it encourages happiness without thinking about the body, and at the same time it suggests that struggling with physical impairment may not be the right way to approach the subject. Nevertheless, despite trying very hard to offer an alternative discourse to the cultural images attached to the aging body, both Hayley's and Kerry's narratives can only touch upon a new cultural imaginary. Even though they attempt to describe the aging body in terms of illness, they both tend to fall back into the discourse of 'old' age. However, the emphasis on a meaningful life is transferrable to lives of the elderly.

Hayley Okines' story visualizes issues of the aging body in a public context, a visibility that serves as a first step towards a reimagining of the connotations of the aging body. Such reconsideration, in turn, can be applied not only to the phenomenon of progeria as an extraordinary case of aging but also to the process of aging in general. The same mechanism holds true for the narrative's depiction of networks of care. In *Old Before my Time*, it becomes clear that care needs to be regarded as a communal effort in order to provide help and hope for all those involved. At the same time, the narrative advocates for a reevaluation of systems of care away from derogatory stereotypes of death, neglect, and disengagement. The things the reader learns from the Okines' network of care and the community supporting them is ultimately applicable to many situations involving a need for care, including 'old' age.



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

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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 institution-

alized 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.

## 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 Flue. 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.





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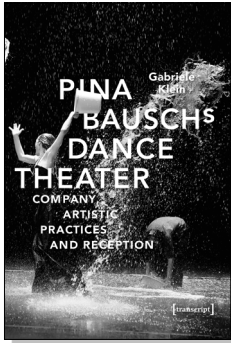
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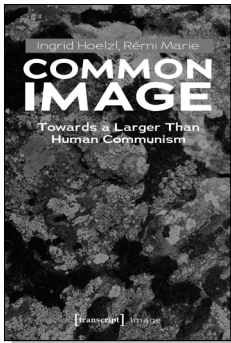
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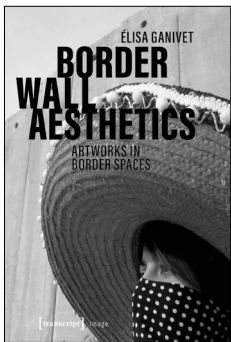
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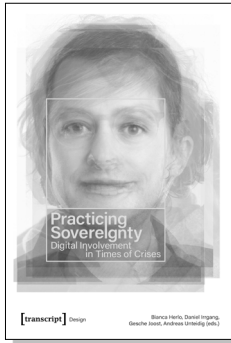
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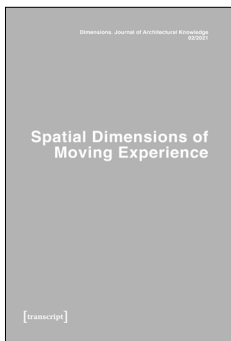
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