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

Old Before My Time: Hayley Okines' Life with Progeria, the (auto)biography of Hayley Okines and her mother Kerry Okines[1] 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.[2] 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.[3] 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 practice (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 am 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 'ban' 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[4], 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[5] 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 redefinition 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.[6] '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.[7] 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 overprotective 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.[8]

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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 cultiral 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.