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Taking Care and Taking Risks: Identity Formation in Young Adults with Chronic Health Conditions

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TAKING CARE AND TAKING RISKS:
IDENTITY FORMATION IN YOUNG ADULTS WITH CHRONIC HEALTH CONDITIONS

by

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Taking Care and Taking Risks: Identity Formation in Young Adults with Chronic Health
Conditions
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The final copy of this thesis has been examined by the signatories, and we find that both the content and the form meet acceptable presentation standards of scholarly work in the above mentioned discipline.

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Taking Care and Taking Risks: Identity Formation in Young Adults with Chronic Health
Conditions

Thesis directed by Professor Leslie Irvine

Research on chronic conditions and their impact on individual identity often center on biographical disruption or the idea of a bifurcation of “before and after” identities. Moreover, little research examines identity formation in young adults with chronic health conditions despite the growth of this population. This thesis focuses on young adults’ narrative identities, both in terms of how young adults describe the transition to adulthood and how cultural ideals of young adulthood and actors from institutions influence how they describe themselves. Using 22 in-depth qualitative interviews, this study reveals how young adults either distance themselves from their conditions or move to acceptance through the narratives they tell about their health, feelings, and behaviors. These positions influence how they create identities, becoming either “risk-takers” or “caretakers.” These identities have implications for decisions as illustrated here by the choices interviewees make to demonstrate their health as a status. This research suggests that identity confirmation by others forms an integral part of the nexus of health and the life course, shaping how adolescents make the transition into young adulthood and take on health identities. Identity confirmation from others gives some young adults with chronic conditions room to integrate their conditions into their narrative identities. This study reveals the social nature of young adult identities, and the importance of health to them, precisely because it uses cases of young adults who must transition to adulthood in alternative ways.

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Health has long been a concern for scholars interested in identity. Chronic medical conditions have proven to be a challenge to how individuals navigate daily tasks but also catalyze changes in how people with conditions see themselves.

The onset of a severe medical condition in childhood has far-reaching implications for the transition to young adulthood (Emerson et al., 2012; Mann and Honeycutt, 2014; Mann and Wittenburg, 2015; Maslow et al., 2011; Stam et al., 2006; Verhoof et al., 2014). However, such a transition often lacks theorization from a life course perspective (Bray et al., 2014; Williams, 2000). Advances in medicine have ensured more children facing serious medical conditions in childhood survive to young adulthood, defined here as 18 to 30 years old. While some children with conditions enter young adulthood without any physical or psychological complications, the young adults in this study had onsets of chronic medical conditions in childhood.

Quantitative work often focuses on how poor childhood health, usually caused by poverty, has implications in adulthood (Brian Brown and Lichter, 2006; Umberson et al., 2014). However, we do not know much about how young adults understand their identities about their conditions. Further, much work centers on how parents navigate childhood medical conditions but do not focus on the processes through which young adults develop their identities (Bray et al., 2014; Kirk, 2008; Taylor, 2003).

Here my work centers on how young adults with chronic health conditions beginning in childhood make sense of their conditions in young adulthood. Clear patterns emerged in how young adults talked about their conditions when constructing narrative identities, or “a person’s internalized and evolving life story, integrating the reconstructed past and imagined future to provide life with some degree of unity and purpose” (McAdams and McLean, 2013). Emerging

adulthood theory contends young adults go through a period of prolonged adolescence, with hallmarks such as moving out of education to employment signaling adulthood (Arnett, 2000). Further, such emerging adults are expected to be healthy culturally despite actual disparities in health among the population (Bonnie et al., 2014). Many young adults with chronic conditions cannot live up to cultural expectations of young adulthood (Dumas et al., 2015; Liddiard and Slater, 2017; Mann and Wittenburg, 2015). Further, they are not remaking identities via a “biographical disruption” framework because they do not fall victim to a before/after identity dichotomy (Bray et al., 2014; Williams, 2000). Instead, through identity confirmation, young adults with chronic conditions organize their young adult identities in conjunction with their conditions to create cohesive narrative identities in which they identify as healthy.

This study addresses three questions with the current population: How do young adults consider chronic conditions regarding their narrative identities? What is the process of creating these identities? How do identities influence their decisions around health?

LITERATURE REVIEW

Narrative Identity, the Life Course, and Health

Narrative identity is a facet of McAdam’s (1985) three levels of personality. The theory marks the use of life stories to create meaningful identities, particularly around adversity. Narratives can also accomplish redemption (Irvine, 2013), and in the past, serious medical conditions were a mechanism of redemption for individuals (Frank, 1995; McAdams and McLean, 2013). The existence of the “wounded storyteller” has been previously documented (Frank, 1995).

Individuals must undergo identity transformation once they experience a serious medical challenge, regardless of the physical nature of their conditions (Charmaz, 1995; Frank, 1995).

Narrative identities and Erikson's stages of psycho-social development are intertwined (Erikson and Erikson, 1998; McAdams, 1985). Erikson (1998) characterized development through cumulative stages, meaning that each stage of the life course is dependent on how the previous resolution. Individuals age into life stages, such as childhood into adolescences, acquiring new virtues to face the unique situations of each phase. The beginnings of narrative identities form in childhood, where children learn from their parents how to shape understandings of past experiences, present behavior, and future aspirations (Pasupathi and Hoyt, 2009). Adolescence, where life stories begin to develop more fully (Habermas and Bluck, 2000; McAdams, 1985), is described by Erikson as a struggle between identity and identity confusion.

Bury (1982) first pointed to chronic illness as a biographical disruption. Charmaz (1995) and Frank (1995) have chronicled the ways chronic conditions force identity change. This disruption influences the ways people construct identities. Charmaz explains strategies to live with chronic conditions, including minimizing and adapting in particular. When individuals with chronic conditions minimize the conditions, they often feel alienation from their bodies. They distance themselves from their bodies in what Charmaz calls "objectification," and they continue to fight for mastery over their bodies. Charmaz claims that individuals with chronic health conditions employ "minimizing" to "preserve a sense of unity between the body and self" they experienced before the onset of their condition (Charmaz, 1995: 658)

Individuals adapting to their conditions live with them, but neither surrender to them nor live for them. They do not wish for full recoveries, nor do they fight their bodies when they fail to meet the cultural standard (Charmaz, 1995).

A quantitative study by Chalk (2016) found better self-rated self-esteem scores among young adults with health conditions who identified as disabled than among those eschewing the

disability label. Feelings of acceptance of disability resulted in better mental health (Verhoof et al., 2014). This protective effect connects to narrative identity; narrators who craft life stories with “redemptive meanings in suffering and adversity, and who construct life stories featuring themes of personal agency and exploration, tend to enjoy higher levels of mental health, well-being, and maturity” (McAdams and McLean, 2013: 233).

However, age is a crucial mediator between a medical condition and subsequent responses (Grinyer, 2007; Williams, 2000). The circumstance of children and young adults with chronic conditions are “fundamentally different” because of their situation at an earlier point in the life course (Bray et al., 2014), but little is known about how the earlier onset of a medical condition influences identity, principally narrative identity.

Childhood as a Critical Point

Experiences of adversity in childhood shape but do not determine the trajectory of the rest of one’s life (Elder, 1998). However, a traumatic event in childhood shapes how further stages are handled precisely because development is cumulative, and early resolutions to challenges of identity shape how individuals will face later stages (Erikson and Erikson, 1998). Though scholars have often spoken about the “long arm of childhood” (Brian Brown and Lichter, 2006; Umberson et al., 2014), most research focuses on how poor health stemming from low socioeconomic status can influence health in young adulthood (Case et al., 2005; Mulatu and Schooler, 2002; Palloni, 2006). The gap in the literature has been documented but unaddressed (Margolis, 2010). A small but growing amount of literature looks at outcomes for children with disability statuses that are not directly related to poverty, meaning medical conditions that are

caused by genetic predispositions, injuries, or environmental factors that are not associated with lower socioeconomic status are becoming more predominant in the literature.

How children feel about chronic conditions in childhood is social (Atkin and Ahmad, 2001). Children with medical conditions navigate institutions such as hospitals (Berrios-Rivera et al., 2008; Lambert et al., 2014), schools (Hawley, 2012), or the family (Bray et al., 2014; Taylor et al., 2008) in quite a different manner from healthy counterparts. Children with health conditions are generally in sustained contact with healthcare professionals. Medical staff often concentrate on “curing” or improving health outcomes for the child, although researchers have called for changes in how quality-of-life is assessed to include psychosocial factors (Quinn et al., 2013). Indeed, even work challenging the theory of biographical disruption focuses on how “normal” a child with a chronic illness can strive to be (Atkin and Ahmad, 2001; Grinyer, 2007). Medical professionals often lack the understanding of how youth experience the world, which may differ their own experiences (Nevins, 2002; Simons and Moseley, 2009). While a child may have supportive healthcare professionals in their lives, they may still encounter other barriers. In a study of children with brain injuries teachers engaged in behavior modification strategies that actively undermined self-esteem in their students with disabilities (Hawley, 2012).

Parents are often characterized as a child as either the greatest ally or source of tension for a child with a medical condition (Taylor et al., 2008). Parents can feel pressured to cultivate children who succeed by normative measures (Lareau, 2011), which may not always be obtainable for children with medical conditions. Such experiences of difficulty in childhood influence later stages of the life course, but the social interactions during childhood dictate how they do so.

Young Adulthood

Life course theory conceptualizes aging as moving in to and out of transitional stages over the period of an individual's life (Arnett, 2000; Shanahan, 2000). Researchers have closely theorized young adulthood following Arnett's (2000) research on "emerging adulthood." Emerging adulthood posits that, in the face of large demographic shifts, young adulthood now involves a slow transition from late adolescence through the twenties. Five main rites of passage characterize the transition; marriage, financial independence, parenthood, and moving from educational pursuits to full-time work (Shanahan, 2000). However, the theory has been heavily critiqued (Arnett, 2000; Benson and Furstenberg, 2006; du Bois-Reymond, 2016; Silva, 2012). Nearly twenty years ago, Shanahan (2000) characterized young adulthood as "less... a discrete set of experiences that are temporarily bound in the life course and more as an integral part of a biography that reflects the early experiences of youth and also that shapes later life" (Shanahan, 2000: 668). In particular, the "big five" hallmarks of young adulthood have been contested as self-actualization has proven to be important to identity in young adulthood (du Bois-Reymond, 2016; Silva, 2012). These markers reduce young adulthood to an experience that does not vary, despite qualitatively different experiences of the life course in terms of race, gender, and class specifically. Additionally, many of these markers prove elusive for low-income young adults; wealthier young adults are more likely to feel they are "emerging" adults, and that they are not fully adults later into the twenties (Johnson et al., 2006).

Emerging adulthood certainly leaves many young adults behind. Research suggests this includes young adults with medical conditions (Chalk, 2016; Charmaz, 2010; Emerson et al., 2012; Mann and Honeycutt, 2014; Turner et al., 2011). While they advance to the next stage of development, the ways they do so do not always mirror their peers. Often these hallmarks elude

them. Despite being financially unable to attain what emerging adulthood suggests is the finish line, adolescents facing adversity are much more likely to consider themselves as adults (Hendry and Kloep, 2010; Johnson and Mollborn, 2009). Relative age is often more important to identities of adulthood than chronological age. Some groups of young adults who cannot obtain the major five hallmarks in normative ways turn to therapeutic narratives of the self. Instead of categorizing their entrance into young adulthood by entering new roles, they argue that adulthood means shouldering responsibility (Silva, 2012). Nevertheless, no extant research has examined how young adulthood and health may inform each other regarding identity construction.

Young adults are assumed healthy, despite disparities in actual health. They are expected to be healthier than teenagers, who are allegedly unable to care for themselves, but also healthier than older adults who have accrued more physical conditions (Bonnie et al., 2014). Because many youths are generally no longer monitored by their parents, the usual markers of health lifestyles in young adulthood involve risky behavior. Young adults are supposedly able to engage in behavior such as all-nighters and poor diet precisely *because* their bodies are healthy enough to handle those stressors (Lawrence et al., 2017).

Young adults with chronic conditions are frequently unable to make this transition in the same way counterparts do. Despite expressing similar aspirations as their peers (Bray et al., 2014; Emerson et al., 2012; Taylor et al., 2008), disabled adults are 50 percent less likely to have jobs match their interests and capabilities (Turner et al., 2011). Although most young adults with chronic conditions graduate from high school or hold jobs, they are much less likely than their peers to do either (Maslow et al., 2011).

The disadvantages in outcomes no doubt plays a role in how these youth with chronic conditions see themselves. Some research has argued young adults with disabilities face structural difficulties in maintaining meaningful social networks of peers as well as other young adults, as evidenced by the amount of time they spend alone (Muir et al. 2009). The transition to young adulthood in relation to identity construction is highly social (Atkin and Ahmad, 2001; Bray et al., 2014; Taylor et al., 2008). Having a chronic condition may complicate the transition, but such young adults do not grow up in a vacuum. Medical conditions influence the trajectory of a young person, but also their aspirations and relationships (Bray et al., 2014), and thus identity is socially constructed.

Much of the previous literature on identity and chronic health conditions focuses on biographical disruption in adults. This theory is foundational to the current study, which seeks to examine the impacts of health on identity in young adults themselves because they did not have a conception of themselves as adults without their health conditions. Therefore, analyzing the narrative identities they create around these topics can provide insight into identities built around health and certain life course stages. Further, it is imperative to appreciate just how children with chronic health conditions navigate institutions as they move into adulthood because identity construction is inherently social and relies on interactions with others. An understanding of the prominent theory of emerging adulthood, and the realities of young adults with chronic conditions in their ability to meet normative cultural hallmarks drives this study's interest in how young adults experience this particular time in the life course.

METHODS

I conducted 22 interviews from March to November of 2017. The young adults I interviewed were ages 19 to 30. They all had experienced the onset of a serious medical condition before turning 18 years old. I used a convenience sample. I recruited using posters and by making announcements in sociology classes, but these strategies generated few responses. I was more successful reaching out to people whom I knew had experienced serious medical conditions in childhood. This strategy had two benefits. First, it offered a level of comfort during interviews. Throughout my life, peers have been open with me disclosing their medical experiences. All of the members of my immediate family have had medical difficulties and I did not hide that this was the case. Many of my interviewees described their weariness in being the first person with a condition a stranger might meet. When I expressed surprise at this while interviewing my friend Jennifer,¹ she pointed out, “You have to realize, you’re from [a metro area], and your mom is disabled, and your dad like passed away and he went through a whole medical thing...so, most people...it’s not that they don’t encounter people who are disabled, it’s that they don’t have a person who’s disabled that they talk to.”

My comfort around disability may have contributed to some interviewees’ willingness to talk to me. Choosing to interview friends and people I had known to have conditions in childhood provided a second advantage. This manner of recruitment I used led me to find more people unengaged with the medical system (Charmaz, 1991). Recruiting interviewees outside of hospitals was paramount, posing a counterpoint to the majority of studies, which recruit through medical institutions (Earle et al., 2005; Heaton, 2015; Rosen et al., 2003). Indeed, even literature attempting to capture how young people feel about their conditions and identities interviewed parents (Bray et al., 2014; Grinyer, 2007; Kirk, 2008) or recruited through medical institutions

¹ I use pseudonyms, mostly chosen by interviewees, to preserve confidentiality.

(Atkin and Ahmad, 2001; Kirk, 2008; Monaghan and Gabe, 2015). I wanted to obtain data from people choosing to abstain from healthcare institutions. Some interviewees were told they still required constant contact with medical professionals but decided to disengage with the medical institution entirely. They represent a sociologically unique perspective in this study.

Some interviewees I knew very well. Some I had lost contact with but had known in childhood. I attempted to establish rapport with interviewees by talking about my family members' experiences or the friend we had in common.

I began broadly with questions, always starting with the following three: To whom do you talk with about your condition? Do you have a run-down you always use to explain it? Did this change from childhood to adulthood? I then would adopt whatever language the interviewee used. Some interviewees described their conditions or diagnoses, while some freely used the word disability. I disclosed that I do not consider myself to be a person with a disability, nor did I have poor health in childhood. However, as discussed above, my experiences with my family did broker trust in some of my participants, and some commented they would not have agreed to the interview if they had not known I was familiar with medical conditions.

I chose to use the criteria of self-definition because I am neither medical doctor nor an arbitrator of what is medically serious. Moreover, I am interested in *perceptions* of being ill. My choice proved fortuitous, as some interviewees felt they still lack validation from the medical system. I am not interested in the "objective truth" my interviewees may offer regarding their retrospective accounts and current opinions. As such, my work is inductive and interpretivist (Roth and Mehta, 2002).

I carefully elicited full descriptions of exactly what they meant, especially from those with whom I am friends. My outsider status helped to facilitate clear narratives, as I encouraged

participants to explain their experiences fully because of my lack of familiarity (Wilkins, 2012). However, I am no a stranger to what Kafer (2013) calls “crip politics,” despite being able-bodied myself (Kafer, 2013); I had enough knowledge about medical procedures and stigma to keep interviewees comfortable. Sometimes their stories did not align with my recollection of events they had experienced. The discontinuity remained unimportant, as their understandings of their conditions mattered to me. I used an open-ended interview guide in the sense that I asked key questions of all interviewees, but interviewees mainly drove their interviews.

I obtained approval for this research from my university’s Institutional Review Board. Every interviewee consented both in writing and verbally. Interviews took place in person in Colorado and New York, and over Skype for interviewees living in other locations. They averaged about an hour long, with the shortest being 37 minutes long and the longest being nearly three hours. I audio recorded interviews that took place in person, and video recorded interviews over Skype. A third transcribed my interviews, and I checked for their accuracy. I coded my data using the software NVivo.

I worked inductively to focus on the construction of young adult identities, medicalized identities, and how both influence decisions about health. In line with the constant comparative method (Glaser, 1965), I compared all new cases to existing data and wrote memos to expand on theoretical findings. I employed grounded theory from a constructivist lens, meaning I worked inductively to find theoretical threads in my data (Charmaz, 2014). I coded data first broadly and then more specifically to explore the nuance of the narratives of my interviewees (Saldaña, 2013). Additionally, I created memos on my emotional reactions as a way to hone my analysis (Dunn 2009).

Characteristics of the Sample

Overall, I interviewed 13 women, 7 men, and 2 people identifying as non-binary. Five of the people in my study defined their sexuality as queer voluntarily and without prompting. The majority (17) were white. Due to the lack of emphasis on young adults, existing data does not capture the demographics of young adults who identify as having a disability. I am unable to make comparisons between my sample and the broadly population without further study. They resided primarily in Colorado and New York, where my social networks are located. However, about a third of the interviewees resided in other states.

The conditions interviewees volunteered as their diagnoses ranged drastically concerning severity, duration, and how common they are considered. The most frequent conditions were cancer, diabetes, cerebral palsy, and mental health diagnoses (which may be caused by a physical condition). Doctors had told some interviewees they were cured. For example, Marie, who had leukemia in childhood, was surprised at 30 years old to learn that her treatments may cause infertility because she thought she would not face further complications. However, all of my interviewees except Rick reported having physical complications. Most described their conditions as disabling or chronic. Most mentioned or suspected psychological effects such as depression, OCD, and learning disabilities, though only a few had received diagnoses. The age of onset for interviewees varied from birth to age 17. Those with later onsets cited more trouble obtaining diagnoses for their conditions. For more demographic information, including the types of self-defined diagnoses, please see Table 1.

Most of the young adults I interviewed had private insurance, access to adequate if not top healthcare institutions, and had specifically mothers, in particular, who could cut back on work to take care of them. Three interviewees experienced poverty partly due to their condition,

representing what I assume is a more common experience than what I captured. While I actively recruited for people of color and people from low income backgrounds, such analysis on these social factors is beyond the scope of this article.

Overall, the sample should represent a best-case scenario in terms of medical treatment. I assume that many of the interviewees very well may have received the most medically sound treatment available in the United States. With one exception, all interviewees had negative experiences with healthcare professionals, including doctors.²

Many interviewees had worked hard to avoid hospitalization altogether in both childhood and adulthood. For example, Mary did not go to a doctor when she had a seizure related to her diabetes, for example. Some do not engage with doctors at the time of the interviews, although nearly all had done so frequently in childhood.³ This disengagement is especially true of those interviewees diagnosed in their teens; they typically had more distrust of doctors because they still awaited a diagnosis despite constant contact with doctors. Interviewees described fears of needles or liquid medicine or other hallmarks of medical treatment. A few interviewees described disruptions to their education, while others said their limited mobility or time in doctors' offices encouraged them to excel at school. Though the sample is highly educated, some interviewees such as Alexa and Kim cited their conditions as barriers to higher education.

The background of these patients, especially the level of support they received in childhood, allowed me to examine identity confirmation closely as the way young adults move to

² Nadiya's father is a doctor. In the findings section I detail the impact this had on her recovery from cancer.

³ In a contrast to Nadiya's experience, Aurora refused medical treatment because her father was the top child psychologist in the state. She began to distrust doctors because her father did not notice her symptoms.

acceptance specifically. Such background also provides context for how enactment of health decisions and young adult identities matter in the study.

FINDINGS

Disruptions of normal development in childhood (Erikson and Erikson, 1998) are common to young adults who had the onset of chronic conditions in childhood. Additionally, the onset of chronic conditions in childhood eliminates this before/after identity crisis so heavily drawn upon in research on chronic conditions and identity, especially in the context biographical disruption (Bray et al., 2014; Williams, 2000). This raises questions of what narrative identities young adults with chronic conditions have available to them. As I demonstrate here, young adults with chronic conditions either *distance themselves* from their conditions in a bid to seem like they are achieving emerging adulthood as cultural standards dictate, or they *accept* their conditions and integrate them into their identities. This produces two kinds of young adults; “the risk takers” and the “care takers.” These narrative identities influence the stories interviewees tell about their health.

I chose the interviewees highlighted here because they represent common experiences and themes in the data. For distancing, Tyler’s narrative elucidated how a lack of identity confirmation from doctors, via an absence of a diagnosis, necessitates distancing strategies. He also displayed how alienation from the body operates as a way of distancing from his medical condition. Conversely, Brian was an interesting case because his condition was visible, but his parents had expectations for him to be as “normal” as possible. Further, he engaged in downplaying and risky behavior to show how “healthy” he was. I included Anna as an example of someone transitioning from distancing to acceptance. Her narrative showed her ability to

orchestrate changes in how she interacted with institutions to facilitate identity confirmation. Nadiya represented an example of acceptance because she emphasized the importance of institutional support, spoke openly about her condition, and stressed of taking care of her body. Jennifer served as last example of acceptance. She illustrated the importance of supportive family to an acceptance identity, and the do-it-yourself use of “natural” remedies as a way to enact health that was normative to young adulthood. Each case represented patterns revealed in the dataset.

DISTANCING AND RISK TAKING

Tyler was a graduate student at a neighboring university. We had both attended a meeting for graduate students on my campus. He had parked close to our location and offered to give me a ride to my car. I sat in the front seat of his dark but very clean sedan. I had not known he had a medical condition, but when I started talking about my research, he immediately volunteered. Later the same month we met in my office. He sat in a chair across from me and crossed his legs. He looked comfortable but collected. He was dressed nicely in a sweater and some slacks. He was 27 but looked a bit young for his age, possibly because he was underweight, something he later lamented in the interview. I found him incredibly intelligent. He was careful with his words, choosing them slowly and deliberately.

Tyler was the second person I interviewed. Although at this point we were friends and had a rapport, I was careful not to interrupt him. I began by asking him if he talked about his health condition, which he characterized as frequent vomiting and inability to hold down food. Although Tyler and his family believed that he was born with the condition, it had got particularly “bad” during his senior year of high school. He missed most of his classes. He told

me he talks about his health only with people who know him, because as he put it, “I find it hard to talk about because it’s something that I feel like I would be very judged for. Uh, which, which means I tend to avoid it whenever I meet someone.” He also worried that others would perceive his disclosure of his condition as using it as an excuse. Both a discomfort with disclosure and the fear of a condition looking like an excuse was a common answer among people who distance themselves from their conditions and bodies. Many people with chronic conditions worry about the social repercussions of revealing they have a medical condition and a difference in treatment from others because of the condition (Charmaz, 1991).

Lack of support from the healthcare institution

I asked how Tyler explained his condition, but since he often does not do so, he told me his feelings about it. He said, “I describe it as something that is in part psychological and in part organic. I think that it is definitely a physical anomaly but I, even though I was apprehensive about the psychological diagnosis at first, I’ve since accepted that there is a psychological component.” I then asked him whether his doctors and other healthcare professionals supported the view of his condition as both physical and psychological. Tyler’s eyes narrowed, and he crossed his arms. “No. Absolutely not. Uh, my healthcare providers want to see it as purely psychological. And I’ve had every test under the sun, or at least almost every test under the sun. And since those tests didn’t come back with anything conclusive, they essentially shipped me off to psychology.”

I pressed further. “Was it hard for you both in childhood and young adulthood to be sort of denied a diagnosis?” I asked. He responded:

Absolutely. Absolutely it was, you know, it's something that I still am searching for today. Because I feel like with a diagnosis even if the diagnosis is something that medically I can't get help for, I think that there's power in a name. And simply assigning a name to it would help me confront it. A little bit more than the nebulous nature that it has afflicted with me so far.

Unfortunately, Tyler's story of misdiagnoses and the anguish of the pain he endured were not uncommon to my sample. Six other interviewees had trouble securing diagnoses from doctors. Much of the time, this was because their onset was in their teenage years, or they had not received a concrete medical diagnosis before then. Twelve interviewees, spanning all categories of accepting, transitioning, and distancing, said healthcare works did not take their pain seriously. Tyler, like three other interviewees, considered suicide because he doubted he would ever get a diagnosis and experienced an unbearable amount of pain. Although doctors never offered him a "Do-Not-Resuscitate Order, Tyler would have agreed upon one had it been offered. In terms of developing a narrative identity, a doctor's disbelief of a chronic condition often hindered a young adult's ability to reconcile their medical status with their stories about themselves. Of course, the healthcare institution was not the sole determinant of whether a young adult used distancing strategies. Family, educators, and the culture of a hometown also played a role. Tyler said his family believed his condition was mainly psychological.

Alienation from the body

Tyler described alienation from his body, which I attributed to the denial of his identity as a person with a chronic condition. When I asked him how he felt about his body, he said quietly, "I live in my body. Much like living in, you know, a house or something. I might not be necessarily

representative of the person inside.” Tyler used distancing to construct a narrative identity that communicates that he is healthy, and therefore, normal, by the cultural standards for young adulthood. However, due to the dynamic nature of identity, distancing is not a permanent solution. Tyler and I talked again nearly a year after his interview. He said his doctors had finally agreed, as a “shot in the dark,” to prescribe him an appetite stimulant and anti-smooth muscle spastic. He was starting to hold down more food. He was on his way to employing strategies of acceptance, meaning moving to integrating his condition into his identity with the support of social relations.

Brian's story

Brian and I had worked together in college at the tutoring center. I was a tutor, and he was a graduate assistant. Brian had often made easy jokes about his motorized scooter in college, saying he was going to “step away from his desk” or telling entertaining stories about braving barriers like snow or construction on campus. When I went back to my home state to do interviews, I reached out to Brian. I had not initially scheduled him for an interview, perhaps because he had downplayed his condition so often that and I had forgotten he fit my criteria. He said he was in, as long as I thought he qualified. We ended up doing a skype interview.

Brian cheerily answered my Skype call seated in his home office in his childhood home. He had more facial hair than I had remembered. He was 26 with brown hair and eyes, and he wore a casual but stylish gray and black long sleeve shirt on. His body tells strangers that he has cerebral palsy before he does. He admitted that he did not typically disclose because “it’s pretty noticeable,” and that when he first meets people, he first works to establish he is “mentally all there.” He explained that strangers often addressed the people with him rather than speaking to

him directly or they treated him like a child. Other interviewees with visible conditions mentioned similar experiences.

Downplaying

By the time I had interviewed Brian, I had already noticed that people were either distancing from or accepting their conditions. At the time, I had thought that people who were distancing themselves from their bodies and conditions did so because they could. Put another way, I expected people with visible conditions to employ acceptance strategies. Brian described how strangers would say that they are “so sorry” when he explained cerebral palsy to them. Brian showed his usual reaction, shrugging and saying “there’s no reason [to apologize], because I’ve dealt with this my entire life, so this is my normal. This is all I know.” I expected to lump him into the acceptance camp (Zerubavel, 1996). However, he immediately proved me wrong by explaining how often he downplayed, or what I characterized as publicly minimizing the severity of a condition in terms of ability, pain, or emotional impact. Though he said he had not considered whether he downplayed before, he said, “yep, [I downplay] all the time. For me, I’m used to that at this point, so I don’t necessarily see it as that anymore, because I feel like I’ve done that so often it’s just like, normal...” My previous understanding of distancing was wrong. Brian demonstrated that an ability to hide a condition was not the sole driving force.

“Normal” capabilities

Brian has never lacked a diagnosis, but this did not mean that others had confirmed his identity as an individual with a chronic condition. Brian said he avoided doctors for most of his life. He was unengaged with the medical system when I interviewed him. He said:

Because I use my walker all the time, my shoulders are pretty screwed up. So, one of the things they were saying is eventually you may want to have surgery on your shoulders. I was like, “yeah, I’m not going to do that,” because they were like, “you may not be able to use your walker anymore.”

Brian valued the independence of using a walker and distancing himself from his condition and the use of a wheelchair, over the opinions of doctors who he believed did not take him seriously. Like many interviewees who did not want to acknowledge their conditions, he avoided other people with chronic conditions and the broader disabled community. His parents told him he was capable of doing what other young adults did. Apparently, they meant being as normal or as much like healthy peers as possible. He described a particular fight he had with his parents in college:

So, there was this one argument about laundry, where they were like “how are you going to do laundry by yourself?” I was like, “look. There are laundry services, so even if I could... I might if I could, if I couldn't I'd just pay for someone to do it.” They were like, “you need to be able to do this independently.” I was like, “I make the decision independently, about laundry service” Boom, we're done.

Brian explicitly equated refusing to acknowledge his condition as a way of “accepting” it. He had secured a good job with a company. He reveled in the fact they did not acknowledge his condition. He complained about dating, saying that after a couple of dates with women who liked him there would come a point where they would break off the relationship because “[they would say], ‘my family doesn't think it's a good idea, because they're like, you're going to have to take care of him.’” Brian longed to achieve all of the hallmarks of young adulthood he thought he was

entitled too. Despite feeling unable to obtain them, Brian characterized his outlook as positive by necessity. Distancing provided a way to create a normative narrative identity.

Risky physical behavior

Distancing strategies, in turn, lead to risky behavior in young adulthood. Some interviewees went beyond hiding their conditions and audaciously engaged in risky behavior to undermine them. I call them the risk takers. Some, like Isabelle and Valerie, did not take care of their bodies, often eating or sleeping less than they needed to. Some, like Don and Anna, would engage in activities such as mountain biking or scuba diving. Brian had his version of risky behavior:

The first time that I walked around [a long road at his college], I did it twice. The first time I did it I was just like, “oh my god. I'm probably going to die, because it's like three miles around and every step that I take I have to lift my body weight in my walker.” So, it's like if a mile is 5,280 steps and, you know, then every step you've got to lift your body weight, that's like 15,000 steps. So, it's kind of interesting because I totally collapsed a few times, the first time I did it. And I was like “that's not good. I should probably stop,” but I kept going because I was like, “I'm going to do this.” And then I did it, and then I couldn't move for like three days...I don't like limits. I don't like when people tell me I can't do something.

I asked him, “even if it's your body telling you that you can't do something?” Brian smiled sheepishly. “Yep,” he answered, shrugging. “That doesn't exist.” Brian engages in risky behavior to complement his narrative identity of a “normal” young adult. For interviewees engaged in distancing, this normal identity necessitated proving they are healthy.

Identity Confirmation and the Transition to Acceptance

Anna had seen my flier at a friend of a friend's house and contacted me. Anna seemed to be good spirits for the interview. She was smiling and laughed often. She was 22 years old. She had her long blond hair in a casual ponytail. Anna had been a serious golf player when she was sixteen and still wore clothing with athletic aesthetics, in this case, a dark blue V-neck t-shirt. She sustained a debilitating back injury, ending her involvement with golf. She was forced to quit and lost touch with most of her friends in the process. Like Tyler, she talked about doctors who did not believe her injury to be real. Doctors often accused her of looking for attention from her parents. Her relationship with her father had become strained because he had been her coach and he said he blamed himself for her injury. Doctors prescribed heavy painkillers. She said,

I wound up where I had to [go to] pain rehabilitation, also being medication rehab. I no longer take any pain meds, and I'm aware that I don't like to be near them. The real concern for me. It's insane because I was addicted to a prescribed medication that was given to me by doctors regularly. Like you're not-that never should have happened. I don't remember like a good eight months of my life because I was heavily medicated.

Anna refused medication at the time of the interview because she felt that the number of painkillers she prescribed was irresponsible and caused her addiction. As a result, Anna did not engage with any medication and distrusted doctors.

Changes in interactions with institutions

Anna had begun her interview by telling me, "I guess it is really strange to have this thing that happened to me." She used language of distancing throughout our time together. She emphasized that she did not disclose her condition because she worried that others would

perceive her as “weak” or “a damsel in distress.” However, Anna was beginning the transition to acceptance, a process she said she was undergoing intentionally. When I asked at the end of her interview if she would like to add anything, she looked up for a moment but spoke confidently, “I think the hardest part of my chronic illness was accepting that I had one.” Although the process seemed individual, as is any process of identity construction, Anna illustrated the social nature of the transition. Anna moved across the country for college and graduate school. She no longer engaged with the doctors who had not believed her. She forced her parents to go to family therapy and encouraged them to be supportive. Moreover, she had begun dating someone who accepted her condition.

Anna’s approach to risk reflected the transition to acceptance. For years after her injury, Anna avoided hospitalization to continue to scuba dive. She described the importance of diving as this: “finally I went under the water, and it was weightless. And I could move.” However, Anna had also started participating in athletic pursuits again but was endeavoring to be safe. She said, “I got back into being an athlete again at a casual, much more casual level. A completely different sport. And with being that I know my limitations.”

ACCEPTANCE AND CARETAKING

Nadiya was no-nonsense and extremely well put together. She wore impeccable makeup, a white dress shirt, and a long skirt. I suggested we walk over to the New York Public Library. We walked along, chatting about our mutual friend who went to college with me and to high school with her. Despite the overcast weather, tourists speaking in many languages were all around us. We went past the marble lions out front but inside found that many sections asked for silence. Finally, we settled into a corner on the stairs on a bench, facing each other.

Nadiya answered many of my questions with “yes” or “no.” She answered quickly and with confidence. She spoke openly about her status as a cancer survivor, even putting it in her Instagram bio. Nadiya was diagnosed with Leukemia at age 11 when she found a painful lump on her knee. Her father, a doctor, knew the bump was a tumor when “it was difficult for [her] to sit in a pretzel shape.” She said her father’s status as a physician might have shielded her from having negative experiences with the healthcare system. She knew such occurrences were prevalent. She thought her experience was exceptional. She reported she did not engage much in the healthcare system. Instead, she went through her father for any medical needs. Like my other interviewees who had cancer, she said she had physical complications from her experiences with the disease and treatments in childhood.

Supported openness around disability

Everyone I interviewed started at a point of distancing. Nadiya credits the supportive environment in the hospital and her family for her transition to acceptance. Her family emigrated from Eastern Europe, and she described them as “very close.” “Everyone’s very supportive,” she said. “I love coming home for dinner...I would much rather spend a weekend hanging out with my folks.” When she first entered remission, she described dealing with low self-esteem and embarrassment due to her hair loss. Now, however, she framed her experiences with cancer as “all positive.” Nadiya found education and charity work empowering. Despite obtaining a prestigious job as a business analyst, she said, “I mean like, I would love to do charity work like full-time.” She described how she had gotten started with her charity:

In Junior High School I sold rubber bracelets, and then donated money to [a charity] ...so that was like my biggest thing. After the Livestrong bracelets came out, I was doing a

bunch of my own. Yeah, and then I started my charity and started like raising. My goal was \$1000, to raise for the Pediatric Cancer Foundation, to walk in the walkathon. That was like minimum team amount to raise. And I raised like \$6000. And I was like “okay, something might come out of this.” And then we raised like over 170 [thousand dollars] since.

Other interviewees, such as Jared, Zoe, and Finn, echoed the sentiment of wanting to help others with chronic conditions. They liked reducing the stigma of chronic conditions. Specifically, they felt if they were open about them less other people with conditions would suffer. Zoe and Finn both work in healthcare because they felt they could “educate” others and help people like them.

Caretaking and partnering with the body

Many acceptors, or even those transitioning, cited an ability to be empathetic because of their medical experiences. Nadiya said she felt such profound empathy for other people facing adversity that she even framed the ability to feel the emotions of others as an occasional hindrance to her emotional health. Nadiya’s caretaker identity as intertwined with her young adult identity involved taking care of others, but also herself via independence and health.

Nadiya says of her health:

I really take care of my body. I work out a lot. But I think that comes back to, I live a very happy life right now. I'm very happy and I do everything that I love, and I think that in order for me to maintain that lifestyle I have to be healthy. So, it always kind of comes back into the circle. I know that if I eat well and I worked out, and if I do the whole nine that I will probably live longer and experience this for longer. That’s kind of my mentality.

Nadiya frames good health as taking care of her body and working with it as a way to experience life after facing her own mortality at a young age. Many interviewees described taking control of their diet and engaging in low-risk forms of exercise as a way to work with their bodies.

Risk-takers and caretakers alike rejected medication. For risk-takers, medical interventions such as drugs indicated they were unlike their peers, ironically utilizing over the counter medications less than counterparts without chronic conditions do. For some caretakers, medicine was not compatible with narrative identity of a “healthy” lifestyle and naturally working with their bodies. Nadiya said of cancer treatments, “I read conspiracy theories all the time [about chemotherapy] and I want to somehow believe it and understand it, especially now that there’s so much talk of immunization and just like population control.” She had doubts about the safety and long-term effects of her treatments despite telling me she had never had a negative experience with medication.

Jennifer’s story

Jennifer and I had worked together for an after-school program when I was in college. We sat in her childhood home on an expansive couch. I had always particularly enjoyed Jennifer’s house, with a warm, playful atmosphere that included a menagerie of cats, dogs, rats, and fish. Bess, a very vocal corgi, was particularly interested in our conversation. Jennifer walked over to the couch with a characteristic hitch in her gait. She had physical arthrogyposes, the symptoms of which included the underdevelopment of her legs. The condition had required many surgeries and bouts of hospitalization throughout her life. At 27 years old, she was one of the few adults in

my life shorter than I am, standing at about four foot seven inches⁴. She had dark hair and eyes with an olive complexion. She spoke with frankness and clever humor. Her interview was my longest at almost three hours, but it was an enjoyable string of poignant stories infused with humor.

“Healthy” alternatives

Jennifer immediately referred to her condition as a disability, which no one employing distancing did. Of disclosing, she said, “I try not to live my life afraid of anything, so I usually just tell people.” She launched into a story about how her grandmother despaired dramatically at her birth when her disability became apparent to her family, but her parents fought for her ever since. They “doctor shopped,” finding the right one who would balance surgeries bolstering her independence. She had many medical complications in both childhood and adult life. She often engaged with the healthcare system due to infections or injuries. From her stories, she portrayed herself as adept at handling the disbelief of doctors or nurses about her pain or symptoms. Like nearly all interviewees, she rejected any medications she does not find essential to her condition. She said, in a way that felt a bit more like a suggestion for my own health, “I looked up ways of dealing with stomach issues without medication and it suggested honey,” Jennifer told me. I laughed. “Okay. So, you’re like shooting honey?” I motioned a taking a shot of alcohol. Jennifer explained:

I keep a honey bear in my desk at work. It works! It really works. I don't take Tylenol unless I have a fever. For whatever reason apparently, people our age aren't supposed to

⁴ When I asked Jennifer her height for this article, she joked, “to add insult to injury I’m also legally a little person.”

really get fevers anymore, but I still do. Yeah, most people in their 20s, 30s, 40s, and 50s don't get fevers. Yeah, they get like 100 and that's it. I get like hey it's a 102.7, that's cool. I don't really take any pills. Unless I have a fever, I don't take Tylenol, Advil, or Motrin or anything. I take turmeric instead. Do you ever take turmeric?

I thought for a moment. "My mom does sometimes," I said. She leaned back and told me, "best stuff in the world." She motioned to her feet. "I take turmeric which helps with swelling. My feet get swollen and my ankles and stuff swell so I take turmeric for that and it helps with circulation, it helps with swelling, memory, headaches, focus."

Jennifer was able to create a narrative identity of health and partnership with her body by emphasizing natural remedies she found on her own. She largely rejected over the counter medication, as well as prescription drugs, which were at odds with how she saw fit to take care of her health.

Early identity confirmation

Jennifer may have been the earliest person in my sample to practice acceptance. Her parents were always supportive of her, balancing her capabilities with high aspirations for her. She said of her childhood:

[At] two and a half, three years old, [my mother] would sit me in the middle of the kitchen table with a stack of plates, stack of knives, stack of forks, and napkins, and it was my job to set the table. I turned my ass around in the middle of the table and set the placemats because, otherwise, we weren't eating dinner. The rules applied for me, and my sister, and my brother. I was a member of the family, I needed to put my weight in.

Jennifer told her family she wanted to die when she was in the fifth grade after some particularly nasty bullying in addition to injuries related to her condition put her out of school. She described her family's support as warm and loving. They ensured that she remained connected to the resources she needed. When she started college, her father helped her sneak the alcohol she had bought into the dorms because she could not carry the bottles on her own. Her transition to acceptance, and her enactment of the signifiers of healthy adulthood was engendered by her supportive family who found doctors who could treat her condition to give her the independence to live as she wanted. She was not particularly worried about the significant hallmarks of young adulthood. Instead, she used a narrative identity in which she was able to achieve her goals on her terms though it meant eschewing the normative path to cultural ideals of young adulthood.

DISCUSSION

In this research, I use stories young adults tell about their experience with chronic conditions to demonstrate how they understand themselves. Next, I argue that identity confirmation situates them as distancing or accepting in young adulthood. Finally, I argue that these positions have influenced how they enact their health behaviors, either taking risks to prove they are healthy or taking care of their health through diet and exercise. This illustrates the importance of good health as a requirement of young adulthood. Put another way, although young adults with serious medical conditions are unable to attain the cultural standards of health, they show being healthy is nevertheless integral to creating a viable young adult identity.

Young adults with medical conditions in childhood who still experience physical and psychological complications from their conditions encounter barriers to accomplishing young

adulthood in the ways that meet broader societal standards. As a result, they employ distancing strategies; people with conditions using distancing separate themselves from their condition to construct an authentic young adult identity. Through other actors in various institutions, some young adults have their identities as young adults with a serious medical condition confirmed. They move to acceptance, integrating their medicalized identities with other aspects of their overall self-concept. Further, both stages of working with identity require enacting health as a marker of young adulthood. Interviewees practicing distancing or acceptance accomplish this as either risk-takers or caretakers, respectively. Those practicing distancing strive to prove their worth as normal young adults. As such, they engage in risky behavior to show they do not need to worry about health. Conversely, young adults who accept their conditions engage in healthy diet and exercise practices. They use such enactment of health to indicate their maturity in adulthood constructing healthy selves working with their conditions.

This study shows that identity confirmation has an impact on the way young adults construct narrative identity, both regarding how they feel about themselves and in how they talk about enacting their own health. Rejecting medication as a means of enacting health in young adulthood was common to both groups, albeit for very different reasons. People who distanced engaged in distancing from medicine because medication indicated they were not normal. Additionally, they rejected it because they did not trust their doctors, who did not confirm their identities, to prescribe them. This also explains disengagement from the medical system overall. Similarly, risky physical behavior demonstrated how healthy a young adult was. Young adults engaging in acceptance, in contrast, strove to show they were responsible and healthy as they worked with their bodies using exercise, diet, and alternative treatments. This was evidence of their independence as they moved through young adulthood in alternative manners.

Chronic illnesses beginning in childhood are essential to examine in terms of identity because the concept of biographical disruption is less salient. Instead, cultural expectations dictate what they should be striving toward or achieving. Further, it is important to note that when a chronic condition has been present in a person's life since childhood, young adults consider chronic conditions in terms of their narrative identities in only two ways; *either* distancing or acceptance, unlike the styles of adaptations other researchers have found (Charmaz, 1991; Frank, 1995; Williams, 2000). The narrative identities and stories of those transitioning from distance to acceptance further highlight the social and cultural factors that narrow young adults to these two identity constructions, and the transition between them.

The particular point of young adulthood exposes the core functions of a narrative identity centered on chronic illness as social. The particular experience of having a chronic condition in childhood exposes the importance of cultural standards in obtaining an ideal of young adulthood. Both distancing and accepting strategies are inherently *social* young adult identities. Distancing allows room for young adults with conditions to pass as "normal," and have access to social resources often associated with being a healthy young adult. These young adults lacked identity confirmation from actors in institutions such as education, family, and healthcare in both childhood and adulthood. As children with chronic conditions, they were not able to successfully use the taken-for-granted resources, nor were they given the room to integrate their conditions into their current identities successfully because they were not taken seriously when they attempted to do so. Young adults with chronic conditions who practiced acceptance could navigate the transition to adulthood openly working with their bodies and medical conditions only because they had identity confirmation from others. Moreover, they knew that others would support them if they take alternative paths to adulthood.

Interviewees' narrative identities in young adulthood indicate just how unobtainable the cultural ideal for young adulthood is. Arnett's (2000) emerging adulthood outlines the five hallmarks that characterize the transition, and perhaps inadvertently, this theory operates under a belief of what normative young adulthood should look like. Both groups of distancers or accepters in my research were unable to achieve these hallmarks in the ways they believed their peers were. Young adults with chronic conditions doing acceptance attempted to move to young adulthood and achieve what markers they saw fit on their own terms. Doctors, parents, and other adults did not give young adults who distanced the opportunity to do so. This caused them to detach from a condition that was undoubtedly a major part of their lives, but the acknowledgment of it meant they felt they could not achieve authentic young adulthood.

While I contribute to many areas of the literature, this study is not without limitations. Future research is needed to examine identity construction in young adults with chronic conditions to capture the nuances of how race and class complicate this process. Regional variation may also uncover differences in a similar regard. This research illustrates the importance of capturing respondents outside of clinical studies, and as such, more research using the direct narratives of young adults with chronic conditions that utilizes random sampling would strengthen the findings laid out here. The interactions of doctors with children and young adults, as explained by the patients themselves, are fertile ground for qualitative research. Finally, research exploring what other stigmatized social locations and situations may necessitate alternative pathways to adulthood, such as the use of distancing and acceptance, are important to displace current research that contributes to the ubiquity of cultural ideals around young adulthood.

Few of us, perhaps only the most privileged, can experience a smooth, delayed transition to adulthood. As other researchers have demonstrated, other identities scaffold young adult identities (Gonzales, 2011; Silva, 2012; Wilkins, 2014). This research adds the dimension of health. The lack of identity confirmation in terms of independent young adulthood and medical identities can have detrimental effects for those growing up with chronic conditions. The project of ensuring a child is perceived as normal, or refusing to acknowledge a condition out of guilt, can mean that a child with a serious health condition becomes an adult who cannot achieve peace with his or her body. A doctor's callous dismissal of a teenager's pain leads to a struggle find a place in young adulthood. This research highlights the importance of working compassionately with children and young adults to recognize alternative paths to adulthood and the conceptions of health that accompany them.

References:

- Arnett, J.J., 2000. Emerging adulthood: A theory of development from the late teens through the twenties. *Am. Psychol.* 55, 469–480. <https://doi.org/10.1037/0003-066X.55.5.469>
- Atkin, K., Ahmad, W.I., 2001. Living a ‘normal’ life: young people coping with thalassaemia major or sickle cell disorder. *Soc. Sci. Med.* 53, 615–626. [https://doi.org/10.1016/S0277-9536\(00\)00364-6](https://doi.org/10.1016/S0277-9536(00)00364-6)
- Benson, J.E., Furstenberg, F.F., 2006. Entry into Adulthood: Are Adult Role Transitions Meaningful Markers of Adult Identity? *Adv. Life Course Res.* 11, 199–224. [https://doi.org/10.1016/S1040-2608\(06\)11008-4](https://doi.org/10.1016/S1040-2608(06)11008-4)
- Berrios-Rivera, R., Rivero-Vergne, A., Romero, I., 2008. The Pediatric Cancer Hospitalization Experience: Reality Co-constructed. *J. Pediatr. Oncol. Nurs.* 25, 340–353. <https://doi.org/10.1177/1043454208323618>
- Bonnie, R.J., Stroud, C., Breiner, H., National Research Council (U.S.), National Research Council (U.S.) (Eds.), 2014. Investing in the health and well-being of young adults. National Academies Press, Washington, D.C.
- Bray, L., Kirk, S., Callery, P., 2014. Developing biographies: the experiences of children, young people and their parents of living with a long-term condition. *Sociol. Health Illn.* 36, 823–839. <https://doi.org/10.1111/1467-9566.12110>
- Brian Brown, J., Lichter, D.T., 2006. Childhood Disadvantage, Adolescent Development, and Pro-Social Behavior in Early Adulthood. *Adv. Life Course Res.* 11, 149–170. [https://doi.org/10.1016/S1040-2608\(06\)11006-0](https://doi.org/10.1016/S1040-2608(06)11006-0)
- Case, A., Fertig, A., Paxson, C., 2005. The lasting impact of childhood health and circumstance. *J. Health Econ.* 24, 365–389. <https://doi.org/10.1016/j.jhealeco.2004.09.008>
- Chalk, H.M., 2016. Disability Self-Categorization in Emerging Adults: Relationship With Self-Esteem, Perceived Esteem, Mindfulness, and Markers of Adulthood. *Emerg. Adulthood* 4, 200–206. <https://doi.org/10.1177/2167696815584540>
- Charmaz, K., 2014. Constructing grounded theory, 2nd edition. ed, Introducing qualitative methods. Sage, London ; Thousand Oaks, Calif.
- Charmaz, K., 2010. Disclosing illness and disability in the workplace. *J. Int. Educ. Bus.* 3, 6–19. <https://doi.org/10.1108/18363261011106858>
- Charmaz, K., 1995. The Body, Identity, and Self: Adapting To Impairment. *Sociol. Q.* 36, 657–680. <https://doi.org/10.1111/j.1533-8525.1995.tb00459.x>
- Charmaz, K., 1991. Good days, bad days: the self in chronic illness and time. Rutgers Univ. Press, New Brunswick, NJ.

- du Bois-Reymond, M., 2016. Emerging Adulthood Theory Under Scrutiny. *Emerg. Adulthood* 4, 242–243. <https://doi.org/10.1177/2167696815614422>
- Dumas, A., Cailbault, I., Perrey, C., Oberlin, O., De Vathaire, F., Amiel, P., 2015. Educational trajectories after childhood cancer: When illness experience matters. *Soc. Sci. Med.* 135, 67–74. <https://doi.org/10.1016/j.socscimed.2015.04.031>
- Dunn, Jennifer L. 2009. "The Path Taken: Opportunity, flexibility, and reflexivity in the field." Pp. 277-288 in *Ethnographies Revisited: constructing theory in the field*, edited by A. J. Puddephatt, W. Saffir, and S. W. Kleinknecht. London, New York: Routledge.
- Earle, E.A., Davies, H., Greenfield, D., Ross, R., Eiser, C., 2005. Follow-up care for childhood cancer survivors: A focus group analysis. *Eur. J. Cancer* 41, 2882–2886. <https://doi.org/10.1016/j.ejca.2005.08.028>
- Elder, G.H., 1998. The Life Course as Developmental Theory. *Child Dev.* 69, 1–12. <https://doi.org/10.1111/j.1467-8624.1998.tb06128.x>
- Emerson, E., Llewellyn, G., Honey, A., Kariuki, M., 2012. Lower well-being of young Australian adults with self-reported disability reflects their poorer living conditions rather than health issues. *Aust. N. Z. J. Public Health* 36, 176–182. <https://doi.org/10.1111/j.1753-6405.2011.00810.x>
- Erikson, E.H., Erikson, J.M., 1998. The life cycle completed, Extended version. ed. W.W. Norton, New York.
- Frank, A.W., 1995. *The Wounded Storyteller: body, illness, and ethics*. University of Chicago Press, Chicago.
- Glaser, B.G., 1965. The Constant Comparative Method of Qualitative Analysis. *Soc. Probl.* 12, 436–445. <https://doi.org/10.2307/798843>
- Gonzales, R.G., 2011. Learning to Be Illegal: Undocumented Youth and Shifting Legal Contexts in the Transition to Adulthood. *Am. Sociol. Rev.* 76, 602–619. <https://doi.org/10.1177/0003122411411901>
- Grinyer, A., 2007. The biographical impact of teenage and adolescent cancer. *Chronic Illn.* 3, 265–277. <https://doi.org/10.1177/1742395307085335>
- Habermas, T., Bluck, S., 2000. Getting a life: The emergence of the life story in adolescence. *Psychol. Bull.* 126, 748–769. <https://doi.org/10.1037//0033-2909.126.5.748>
- Hawley, C.A., 2012. Self-esteem in children after traumatic brain injury: An exploratory study. *NeuroRehabilitation* 30, 173–181.

- Heaton, J., 2015. Use of Social Comparisons in Interviews About Young Adults' Experiences of Chronic Illness. *Qual. Health Res.* 25, 336–347. <https://doi.org/10.1177/1049732314553122>
- Hendry, L.B., Kloep, M., 2010. How universal is emerging adulthood? An empirical example. *J. Youth Stud.* 13, 169–179. <https://doi.org/10.1080/13676260903295067>
- Irvine, L., 2013. Animals as Lifechangers and Lifesavers: Pets in the Redemption Narratives of Homeless People. *J. Contemp. Ethnogr.* 42, 3–30. <https://doi.org/10.1177/0891241612456550>
- Johnson, M.K., Berg, J.A., Sirotzki, T., 2006. Relative Age in the Transition to Adulthood. *Adv. Life Course Res.* 11, 287–316. [https://doi.org/10.1016/S1040-2608\(06\)11011-4](https://doi.org/10.1016/S1040-2608(06)11011-4)
- Johnson, M.K., Mollborn, S., 2009. Growing up Faster, Feeling Older: Hardship in Childhood and Adolescence. *Soc. Psychol. Q.* 72, 39–60. <https://doi.org/10.1177/019027250907200105>
- Kafer, A., 2013. *Feminist, queer, crip*. Indiana University Press, Bloomington, Indiana.
- Kirk, S., 2008. Transitions in the lives of young people with complex healthcare needs. *Child Care Health Dev.* 34, 567–575. <https://doi.org/10.1111/j.1365-2214.2008.00862.x>
- Lambert, V., Coad, J., Hicks, P., Glacken, M., 2014. Social spaces for young children in hospital: Social spaces children in hospital. *Child Care Health Dev.* 40, 195–204. <https://doi.org/10.1111/cch.12016>
- Lareau, A., 2011. *Unequal childhoods: class, race, and family life*, 2nd ed., with an update a decade later. ed. University of California Press, Berkeley.
- Lawrence, E.M., Mollborn, S., Hummer, R.A., 2017. Health lifestyles across the transition to adulthood: Implications for health. *Soc. Sci. Med.* 193, 23–32. <https://doi.org/10.1016/j.socscimed.2017.09.041>
- Liddiard, K., Slater, J., 2017. 'Like, pissing yourself is not a particularly attractive quality, let's be honest': Learning to contain through youth, adulthood, disability and sexuality. *Sexualities* 136346071668867. <https://doi.org/10.1177/1363460716688674>
- Mann, D.R., Honeycutt, T.C., 2014. Is Timing Everything? Disability Onset of Youth and Their Outcomes As Young Adults. *J. Disabil. Policy Stud.* 25, 117–129. <https://doi.org/10.1177/1044207313484176>
- Mann, D.R., Wittenburg, D.C., 2015. Starting Behind: Wage and Employment Differentials Between Young Adults With and Without Disabilities. *J. Disabil. Policy Stud.* 26, 89–99. <https://doi.org/10.1177/1044207315583898>

- Margolis, R., 2010. Childhood morbidity and health in early adulthood: Life course linkages in a high morbidity context. *Adv. Life Course Res.* 15, 132–146. <https://doi.org/10.1016/j.alcr.2010.10.001>
- Maslow, G.R., Haydon, A.A., Ford, C.A., Halpern, C.T., 2011. Young Adult Outcomes of Children Growing Up With Chronic Illness: An Analysis of the National Longitudinal Study of Adolescent Health. *Arch. Pediatr. Adolesc. Med.* 165. <https://doi.org/10.1001/archpediatrics.2010.287>
- McAdams, D.P., 1985. *Power, intimacy, and the life story: personolog. inquiries into identity*, Dorsey professional books. Dorsey Pr, Homewood, Ill.
- McAdams, D.P., McLean, K.C., 2013. Narrative Identity. *Curr. Dir. Psychol. Sci.* 22, 233–238. <https://doi.org/10.1177/0963721413475622>
- Monaghan, L.F., Gabe, J., 2015. Chronic illness as biographical contingency? Young people's experiences of asthma. *Sociol. Health Illn.* 37, 1236–1253. <https://doi.org/10.1111/1467-9566.12301>
- Mulatu, M.S., Schooler, C., 2002. Causal Connections between Socio-Economic Status and Health: Reciprocal Effects and Mediating Mechanisms. *J. Health Soc. Behav.* 43, 22. <https://doi.org/10.2307/3090243>
- Nevins, T.E., 2002. Non-compliance and its management in teenagers. *Pediatr. Transplant.* 6, 475–479. <https://doi.org/10.1034/j.1399-3046.149.ptr1s077.1.x>
- Palloni, A., 2006. Reproducing Inequalities: Luck, Wallets, and the Enduring Effects of Childhood Health. *Demography* 43, 587–615. <https://doi.org/10.1353/dem.2006.0036>
- Pasupathi, M., Hoyt, T., 2009. The development of narrative identity in late adolescence and emergent adulthood: The continued importance of listeners. *Dev. Psychol.* 45, 558–574. <https://doi.org/10.1037/a0014431>
- Quinn, G.P., Huang, I.-C., Murphy, D., Zidonik-Eddelton, K., Krull, K.R., 2013. Missing content from health-related quality of life instruments: interviews with young adult survivors of childhood cancer. *Qual. Life Res.* 22, 111–118. <https://doi.org/10.1007/s11136-012-0120-z>
- Rosen, D.S., Blum, R.W., Britto, M., Sawyer, S.M., Siegel, D.M., 2003. Transition to adult health care for adolescents and young adults with chronic conditions. *J. Adolesc. Health* 33, 309–311. [https://doi.org/10.1016/S1054-139X\(03\)00208-8](https://doi.org/10.1016/S1054-139X(03)00208-8)
- Roth, W.D., Mehta, J.D., 2002. The Rashomon Effect: Combining Positivist and Interpretivist Approaches in the Analysis of Contested Events. *Sociol. Methods Res.* 31, 131–173. <https://doi.org/10.1177/0049124102031002002>

- Saldaña, J., 2013. *The coding manual for qualitative researchers*, 2nd ed. ed. SAGE, Los Angeles.
- Shanahan, M.J., 2000. Pathways to Adulthood in Changing Societies: Variability and Mechanisms in Life Course Perspective. *Annu. Rev. Sociol.* 26, 667–692. <https://doi.org/10.1146/annurev.soc.26.1.667>
- Silva, J.M., 2012. Constructing Adulthood in an Age of Uncertainty. *Am. Sociol. Rev.* 77, 505–522. <https://doi.org/10.1177/0003122412449014>
- Simons, J., Moseley, L., 2009. Influences on nurses' scoring of children's post-operative pain. *J. Child Health Care* 13, 101–115. <https://doi.org/10.1177/1367493509102468>
- Stam, H., Hartman, E.E., Deurloo, J.A., Groothoff, J., Grootenhuis, M.A., 2006. Young Adult Patients with a History of Pediatric Disease: Impact on Course of Life and Transition into Adulthood. *J. Adolesc. Health* 39, 4–13. <https://doi.org/10.1016/j.jadohealth.2005.03.011>
- Taylor, F., 2003. Content Analysis and Gender Stereotypes in Children's Books. *Teach. Sociol.* 31, 300. <https://doi.org/10.2307/3211327>
- Taylor, R.M., Gibson, F., Franck, L.S., 2008. The experience of living with a chronic illness during adolescence: a critical review of the literature. *J. Clin. Nurs.* 17, 3083–3091. <https://doi.org/10.1111/j.1365-2702.2008.02629.x>
- Turner, S., Unkefer, L.C., Cichy, B.E., Peper, C., Juang, J.-P., 2011. Career Interests and Self-Estimated Abilities of Young Adults With Disabilities. *J. Career Assess.* 19, 183–196. <https://doi.org/10.1177/1069072710385651>
- Umberson, D., Williams, K., Thomas, P.A., Liu, H., Thomeer, M.B., 2014. Race, gender, and chains of disadvantage childhood adversity, social relationships, and health. *J. Health Soc. Behav.* 55, 20–38.
- Verhoof, E.J., Maurice-Stam, H., Heymans, H.S., Evers, A.W., Grootenhuis, M.A., 2014. Psychosocial well-being in young adults with chronic illness since childhood: the role of illness cognitions. *Child Adolesc. Psychiatry Ment. Health* 8, 12. <https://doi.org/10.1186/1753-2000-8-12>
- Wilkins, A.C., 2014. Race, Age, and Identity Transformations in the Transition from High School to College for Black and First-generation White Men. *Sociol. Educ.* 87, 171–187. <https://doi.org/10.1177/0038040714537901>
- Wilkins, A.C., 2012. Becoming Black Women: Intimate Stories and Intersectional Identities. *Soc. Psychol. Q.* 75, 173–196. <https://doi.org/10.1177/0190272512440106>

Williams, S., 2000. Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociol. Health Illn.* 22, 40–67. <https://doi.org/10.1111/1467-9566.00191>

Zerubavel, E., 1996. Lumping and splitting: Notes on social classification. *Sociol. Forum* 11, 421–433. <https://doi.org/10.1007/BF02408386>

Table 1. Interviewee demographics. All information excluding the final categorization is a reflection of the definitions of the interviewee.

Name	Age	Gender	Condition	Location	Education	Ethnic Identity	Age of First Diagnosis	Strategy
Brian	25	Man	Cerebral Palsy	New York	Masters	White	Birth	Distancing
Isabelle	21	Nonbinary	Cleft Lip and Palate	North Carolina	In College	Filipina and White	Birth	Distancing
Valerie	24	Nonbinary	Cerebral Palsy	Colorado	In College	White – Ethnically Russian	Birth*	Distancing
Kim [^]	26	Woman	Brain Tumor and Epilepsy	Massachusetts	Some College	Vietnamese and Swedish	4	Distancing [^]
Nel	20	Woman	Depression	Colorado	In College	White – Ethnically Jewish	13	Distancing
Tyler	23	Man	Undiagnosed Stomach Condition and Depression	Colorado	Masters	White	Misdiagnosed at 20	Distancing
Don	21	Man	Histiocytosis	Colorado	In College	White	3	Distancing, start of transition
Maggie	23	Woman	Charcot-Marie-Syndrome	Maine	In Graduate School	White – Ethnically Jewish	11	Transitioning
Lorelai	20	Woman	Eating Disorder and OCD and Anxiety	New York	In College	White – Ethnically Jewish	14	Transitioning
Anna	22	Woman	Injury to the Back	Maine	In Graduate School	White	16	Transitioning
Kate	20	Woman	Celiac Disease	New York	In College	White	17	Transitioning

Aurora	21	Woman	Depression and Anxiety and Posttraumatic Stress Disorder	Colorado	In College	White	21	Transitioning
Tommy	23	Man	Atopic Dermatitis	New York	College	White	Birth	Acceptance
Jennifer	28	Woman	Physical Arthrogryposes	New York	Masters	White – Ethnically Jewish	Birth	Acceptance
Marie	30	Woman	Leukemia	New York	High school	Latina	4	Acceptance
Zoe	24	Woman	Diabetes and PCOS and Anxiety	Massachusetts	College	White	4	Acceptance
Mary	26	Woman	Diabetes	Missouri	Masters	White	7	Acceptance
Jared	23	Man	Leukemia and OCD	Colorado	College	White – Ethnically Jewish	7	Acceptance
Alexa	22	Woman	Stomach Condition and Mental Illness	Colorado	Less Than High School	White – Ethnically Jewish	9	Acceptance
Rick	19	Man	Adrenal Insufficiency	New York	In College	White – Ethnically Jewish	10	Acceptance
Nadiya	25	Woman	Leukemia	New York	College	White – Ethnically Jewish	11	Acceptance
Finn	24	Man	Depression and Anxiety	New York	MSW	White – Ethnically Jewish	13	Acceptance

*Valerie was adopted from Russia at age 4, at which point they began medical treatments.

^Kim leans towards distancing because of her current mental health, which she describes as a depressive state. She sometimes exhibits more signs of acceptance depending on how she is doing psychologically.

Bolded interviewees are featured in the article.