

OFF-TIME ILLNESS: WHEN YOUNG ADULTS  
GET ILLNESSES ASSOCIATED WITH OLD AGE

by

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## DISSERTATION ABSTRACT

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Title: Off-time Illness: When Young Adults get Illnesses Associated with Old Age

This dissertation explores the lived experiences of young adults with cancer through qualitative methods, including 40 in-depth interviews and participant observation. This dissertation extends sociological inquiry to an unexamined population, young adults with cancer. This dissertation focuses on how age and life course state shape illness experience, with attentiveness to variations based on race, class, and gender.

Young adulthood is socially constructed as a period of health, and cancer as a disease of old age. Such assumptions shape age-specific social support systems, medical practices, and perceptions of young adult bodies, impacting young adult experiences of illness. This manuscript analyzes themes of young adults' experience of diagnosis. Young adults experience diagnosis as a multi-sited process encompassing self-diagnosis and professional diagnosis. A central theme in these accounts was the difficulty navigating the age-specific construction of young adulthood as a period of health and cancer as a disease of old age. Second, this project explores the experience of the body for young adults with cancer, focusing on the experience of aberration or out of placeness. Shaped by the institutional environment, aberration represents both the embodied experience of the young adult patient and the positionality of a young adult patient in medical knowledge. This aberration resulted in a loss of agency, especially regarding reproductive autonomy. A third research aim explores the impact of a cancer diagnosis on education,

occupation, family formation, and the role of institutions in supporting or exacerbating this disruption. My findings demonstrate universal disruptions in education, occupation, and family formations. The timing of this disruption during the transitional period of young adulthood resulted in potentially long-term, cascading impacts. Finally, this project explores life after a cancer diagnosis. Young adults expressed uncertainty and a recognition of mortality independent of their health status. In response, young adults employ strategies informed by common sense narratives and ideologies, including bodily labor, family work, and support work.

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## CHAPTER I

### INTRODUCTION

“I was in the process of trying to buy a house. I was trying to start my career. I was trying to get married. I was trying to figure out who I was as a person. And then you get hit with a cancer diagnosis everything stops, no one's taking care of these appointments for me. I have to set them up. You know, I don't know anything about the medical establishment or how any of this works. I don't know anything about insurance. You're at an immediate disadvantage unless you're specifically in that field, or you have adults in your life that can do it for you. So young adults have so much going on without a cancer diagnosis, they're kind of coming of age throughout that whole time of your life into probably into your late thirties. It's a completely different monster. Everything that you've been working towards, it's gone, and you don't really know if it's too late to start back over. People at 28 are either in a relationship, are actively looking for one and a cancer diagnosis stops that. And if, you know, you have someone whose 28 their partner or boyfriend or girlfriend or whatever, who can't handle your diagnosis, they have every right to jump out because it affects their lives too. It's just a different beast completely. And then if you get chemotherapy you've got to think about fertility and if you want kids, if that is even a conversation that you *get* to have. There are so many plates that are spinning when you're, I would say even 18 to late thirties, early forties. It's totally different than being diagnosed at a younger or older stage. I think things are set up kind of working against you.” – *Carlos, 32, Latinx, working-class, diagnosed with stage IV colorectal cancer at 28.*

In the last thirty years, the incidence of cancer in young adults have increased more than in any other age group. Cancer is the leading disease killer for young adults under the age of forty, responsible for nearly 10% of deaths. Each year, more than 80,000 young adults are diagnosed with cancer in the United States. While the cancer survival rates for both children and older adults have improved in recent decades, the survival rates for young adults between 18 and 39 have remained stagnant. Despite these patterns, until recently, the young adult demographic remains largely neglected in both medical and social science research. This project addresses this gap by examining how the life stage influences the experience of illness.

## Overview of the Study

Present society expects individuals to live to the age of 70 and beyond (Kellehear 2007). This expectation shapes how individuals envision the trajectory of their lives. Age is socially constructed and serves as a marker for *when* events should occur along the life course and provides a prescription of how individuals move through time, influencing their understandings of themselves and the social world (Hockey and James 2003). In Western society, catastrophic illnesses are usually associated with later life course stages. This means that a cancer diagnosis can challenge the normal life course expectations for young adults. A cancer diagnosis may cause a biographical disruption, disrupting everyday life and forcing the individual to reevaluate future expectations (Bury 1982). While nursing, psychology, oncology, and social work have begun to examine the experiences of young adults with cancer, their findings often focus on psychological and individual wellbeing, obscuring the role of societal forces in shaping illness experiences (See: Bloom et al. 2001; Rabin et al. 2011). Too often, such studies point to an increasing need for "social support," concealing the structural patterns that socially construct the age-specific vulnerability of young adults with cancer (See: Decker 2007). For example, patterns of late-stage and misdiagnosis are attributed to inexperience with self-advocacy in healthcare rather than access to quality care and institutionalized assumptions about the health of certain bodies. Feelings of anxiety, isolation, and depression incite proposed solutions of young adult-specific support groups and psychological intervention. While important to an individual, this fails to confront, for example, the absence of *any* real social safety net for young adults who experience catastrophic illness. Additionally, the findings of nursing, oncology, and social work typically rely on populations of young

adults with race and class privilege, failing to consider how race, class, and gender intersect with life course stage to impact both institutional arrangements and individual lives. Insight from sociology details how race, class, and gender have been central to the story of cancer, and cancer's disparities, awareness, and experiences have been, and continue to be, shaped by gender and racial politics (Wailoo 2010). The strength of a sociological approach is to consider this personal trouble in the context of history and biography, illuminating how the axis of life course stage intersects with race, class, and gender intersect to shape illness experiences.

This dissertation examines the experience of cancer in young adulthood. How do young adults experience self-diagnosis? How do they experience professional diagnosis? How does a cancer diagnosis impact their lives, from educational and occupational trajectories to relationships, intimacy, and family formations? How do social institutions mitigate or exacerbate the impacts of off-time illness? How does a cancer diagnosis challenge age-specific expectations of young adult bodies? What strategies did young adults employ in life after cancer diagnosis? How are these strategies informed by culture? In answering these questions, I am attentive to variations based on race, class, and gender. Young adults shared similar stories. Stories in which a cancer diagnosis challenged sociocultural expectations of health in young adulthood, unsettled education, work, and family formation, and unsettled how young adults knew and experienced their bodies.

## **Literature Review**

### *Cancer Details*



Cancer refers to a group of diseases characterized by uncontrolled growth and spread of abnormal cells. In the early 19<sup>th</sup> century, a cancer diagnosis carried little likelihood of survival. Over the last century, the five-year survival rate for all cancers has increased from 20% in the 1930s, to 25% in the 1940s, 50% in the 1970s, and 60% in the 1990s. According to the National Cancer Institute, the current 5-year survival rate from 2007-2013 is 67%. While survival rates vary based on type and location, the five-year survival rate for cancers that are localized is over 80%, highlighting the importance of timely diagnosis. Remission refers to the disappearance of the signs and symptoms of cancer. While the forms of remission will not be addressed here, it is important to note that even in complete remission, where all signs and symptoms of cancer have disappeared, cancer may still be in the body. This means that individuals in remission face the threat of recurrence, cancer that returns after six months after initial treatment is completed. Again, the chance of recurrence varies from case to case, depending on patient characteristics, stage at diagnosis, cancer type, and treatment type.

Improvements in survival rates are attributed to biomedical advancements in diagnostic testing and cancer treatment. These improvements have transformed cancers that were once fatal into chronic conditions. Previously treated only with surgery and radiation, the addition of chemotherapy to treatment regimens has dramatically increased survival rates and overall life expectancy for many cancers that were previously considered terminal (Arruebo et al. 2011). A consequence of medical advancements in the treatment of cancer is the emergence of new patient populations of young adults that would previously have had fatal outcomes that are now simultaneously living with the long-term, cascading impacts of a cancer diagnosis, including the ongoing fear of a

recurrence, as well as the long-term side effects and late effects of treatment. For example, reliable chemotherapy regimens and radiotherapy courses have transformed Hodgkin's Lymphoma from a fatal illness to one with an 80% survival rate. Despite these favorable gains in short-term survival rates, Hodgkin's ranks third in Years of Life Lost (YLL), or the years of life lost because of early death, due to treatment-related complications, including secondary malignancies and cardiovascular disease (Ng and Mauch 2009; Ahmadzadeh et al. 2014).

Previous research exploring the young adult demographic has identified long-term physiological and psychological impacts of diagnosis and treatment. Young adults experience the highest rates of mis- and late-stage diagnosis and medical bankruptcy and are characterized as the most underserved population within the cancer community. Many young adult 'survivors' face an increased risk of cardiovascular disease (Ganz et al. 2003), second malignancy (Abrahamsen et al. 2002), and chronic fatigue. Findings also demonstrate increased levels of anxiety, depression, and social isolation (Burgess et al. 2005) and a decrease in perceived emotional support over time (Bloom et al. 2004). This emphasis on physiological and psychosocial wellbeing leaves unexplored how both *vulnerability* and *resilience* are shaped by larger social structures. For example, anxiety, isolation, and depression incite prescriptions of population-specific support groups and psychological intervention, leaving unchallenged the nonexistence of a social safety net to support young adults with catastrophic illnesses. Previous studies have also been narrow in their failure to consider how social location might impact the experience of cancer during young adulthood. I recognize that individuals and bodies are positioned within a matrix of domination, impacted by various axes of privilege and oppression.

Feminist scholarship has established how the intersection of race, class, and gender impacts access and mobilization of resources, the value and treatment of bodies, experiences, and understandings of illness, and where one turns for support.

According to intersectionality, mutually constructed phenomena, like race, class, gender, life course stage, ability, sexuality, and nation, shape social inequality in complex ways (Collins 2015). This project explores how age and life course stage intersects with race, class, and gender to craft unique experiences of vulnerability and resilience for young adults with cancer. In doing so, this illuminates how both vulnerability and resilience are socially constructed for those that experience off-time illness. As a population, young adults experience several health-related disparities, including high rates of late-stage diagnosis and few age-specific clinical trials. Young adults are more likely to be uninsured or to have very limited health insurance, impacting access and utilization of care (Smith and Medalia 2014).

Different bodies may experience different cancers in different locations and stages. While this uniqueness must be recognized, it is imperative to examine the larger patterns in these experiences - experiences with diagnosis, treatment, surveillance, emotion, and embodiment – to illuminate unique sources of both vulnerability - and resilience - based upon shared and similar markers of privilege and oppression. Privilege and oppression not only dictate who is likely to develop cancer in the first place (See: Alvarez and Norton-Smith 2018; Gee and Ford 2011; Hoover et al. 2012; Park and Pellow 2004; Williams and Sternthal 2010), but also how an individual, and their body, experiences diagnosis, treatment, and survivorship. Intersectional analysis marks an important move away from additive approaches to social inequality that assume

experiences are independent, separate, and summative and that identities and oppressions can be ranked (Bowleg 2008). Such approaches ignore intergroup difference (Crenshaw 1991). Intersectionality conceptualizes the relationship between race, class, gender, and other axes of power as interlocking categories that are socially constructed, interdependent, mutually constituted, and relational (Collins 2000; Crenshaw 1991; King 1988; Zinn and Dill 1996). While the category of “age” is included as a social category, it has been largely neglected in sociological inquiry. This project explores how age is positioned within multiple axes of power to shape illness experiences.

### *Life Course and Off-Time(ness)*

The sociology of life course provides important insight into how age impacts the experience of illness. The sociology of life course examines the socially constructed patterns of change that occur from childhood to adulthood. Within a specific culture, individuals follow predictable patterns and transitions. A life course consists of culturally and normatively constructed life stages and age-specific roles. Individuals have several life trajectories or "pathway[s] defined by the aging process or by movement across the age structure" (Elder 1985: 31). Life trajectories are "punctuated" by a sequence of successive life events and transitions (changes in state). An event is understood as an abrupt change, while transitions are gradual changes (Elder 1985: 31). Social norms and expectations dictate the appropriate "timing" of events and transitions along the life course, classifying them as "off-time" or "on-time" (Settersten 2003). In addition to timing, major life events have a presumed order or sequence. When events do not occur in the correct sequence, they can create role conflict, for example, caring for both a child and an aging parent. Young adults that experience a cancer diagnosis violate the timing

and sequence of life events as ill-health is associated with later life stages (Gullette 2017). According to social expectations, young adults should be independent, self-sufficient, and contribute to the political economy. Culturally, young people should be branching out, starting their own lives, and caregiving, either through direct care of older family members and children or through contribution to social security through taxation on their wages (Jain 2013). Importantly, the discourses and assumptions associated with the life course shape the self (Kohli and Meyer 1986; Gubrium and Holstein 1994; Laz 1986).

Expectations attached to life stages are formalized through governmental policies that attach specific responsibilities, rights, and benefits to people at specific *ages* within the life course. Age should not be understood as an individual attribute or chronological fact (Laz 1986). Rather, age reflects – and shapes -- institutions and normative discourses based on cultural expectations about the life course. This conception of age is like that offered recently by Barrett and Michael (2022:185), who conceptualize age as an institution or “a structure of social relations scaffolded by ideologies about age and aging, grounded in practices to sustain them, and enforced by coercive social norms.” Consider the role of age, and the underlying ideologies, reflected in the construction of two age-based insurance policies: Medicare and the Dependent Coverage Mandate of the Affordable Care Act (ACA).

Medicare, which provides national health insurance to those 65 and older, was established in 1965 to protect individuals in the later stages of their life course. Before enactment, 50% of seniors were without health insurance (De Lew and Weinick 2000). While there is a biological basis for the association of ill-health with old age (as health

declines with chronological age), Medicare formalized eligibility based on *age*. Notably, the same ideological association between aging and decline that justifies Medicare has been used to argue for the ineffectiveness of universal healthcare (Gullette 2017; Barrette and Michael 2022)<sup>1</sup>. On the other hand, the 2012 Affordable Care Act (ACA) Dependent Coverage Mandate (DCM) extended the age that adult-children could remain on a parent's health insurance until 26 regardless of marriage, residential, and employment statuses (Simon, Soni, and Cawley 2017). This extension reflected transformations in the young adult life stage and “emerging adulthood.” Like Medicare, the ACA's DCM used age to formalize inclusion based on shifting expectations of parental independence<sup>2</sup>.

### *The Life Stage of Young Adulthood*

Young adulthood is a life course stage of transition and change (Mortimer and Aronson 2000; Shanahan 2000). This dissertation understands young adulthood to be between the ages of 18 – 39. As dependence on family declines, individuals begin to establish careers, intimate relationships, and autonomy (Seiffe-Krenke 2006). Historically, the study of young adulthood has emphasized *transitions* from youth to adulthood, focusing on five life events: completing education, entering the labor force, leaving family, becoming financially independent, getting married, and becoming a parent (Mortimer and Aronson 2000; Shanahan 2000). However, these transitions have

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<sup>1</sup> Importantly, in the context of the US, such policies are not seen as entitlements but rather ‘supplements’ to existing medical and financial resources. In this context, the government does not have the responsibility to care for the needs of sick people.

<sup>2</sup> The coverage provided by the DCP has been uneven, with Black and Latinx patients less likely to have private insurance before and after the Affordable Care Act-Dependent Coverage Provision, compared with white patients (Alvarez et al. 2017). In fact, research demonstrates that the ACA-DCP improved healthcare coverage for those young adults that traditionally have access to resources and healthcare, reinforcing existing patterns of inequality, and that insurance does not directly translate to increased access due to high out-of-pocket costs (Kirchhoff et al. 2012; Tai et al. 2012). Therefore, it is central to focus attention on expanding access for publicly insured groups and decreasing out-of-pocket expenses. While the ACA-DCE did expand coverage for a subset of the young adult population with race and class privilege, it serves to reify existing racial and socioeconomic disparities for those that already experience disparate survival outcomes (Alvarez et al. 2017).

become increasingly complex and non-linear (Furlong 2017). For example, a young adult may live independently for a time and then return to the parental home. Compared to prior generations, contemporary young adults live independently, buy homes, partner, and become parents later in life, necessitating a new life-course phase of emerging adulthood (Arnett 2001; Manning 2020). The increasingly non-linear and complex nature of the transitional period of young adulthood, irrespective of a cancer diagnosis, makes examining a cancer diagnosis in young adulthood even more timely.

Cultural and political shifts of recent decades have made young adulthood a life course stage of increasing instability, making it increasingly challenging to achieve traditional markers of adulthood (Arnett 2010; Furlong 2017). Globalization, technology, the offshore outsourcing of work, the weakening of labor unions, and the spread of neoliberal economic doctrines<sup>3</sup> has resulted in a rise of contingent, or non-regular, work arrangements such as temporary, contract, and part-time work. In this hostile and precarious labor market, employment is insecure and unstable and offers relatively low earnings and benefits (Beck 2000). The emergence of precarious labor markets is central to the experience of young adulthood, as finding – and maintaining – *secure* employment is foundational to independent living, which provides the foundation to achieve additional markers of adulthood (Furlong 2017). Prior scholarship shows that the growth of precarious labor disproportionately impacts young adults who experience the highest rates of unemployment and underemployment and face obstacles in launching their careers. Importantly, these patterns persist despite young adults having the highest levels of post-secondary education (when compared to prior generations). Even highly educated young

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<sup>3</sup> For an in-depth discussion of economic changes, see “Beck, U. (2000). *The brave new world of work*. Malden, MA: Blackwell.”

adults struggle to find secure, full-time employment that meets their education level (Furlong 2017) and experience credential inflation, where jobs require a higher level of education (van de Werfhorst 2009). Moreover, precarious labor can significantly hinder young adult resilience to off-time illnesses as employer benefits like paid time off and health insurance are central to navigating catastrophic illness. I argue that the impact of illness at this critical juncture must be understood in terms of its potential long-term and cascading effects.

### *The Sociological Study of Cancer*

Cancer has been a central focus of the sociology of health and illness. Most of this literature uses qualitative methods to explore lay experiences of cancer, encompassing diagnosis, treatment, and support. Most of this literature focuses on experiences of a specific cancer type, with breast and gynecological cancers being the most common (Kerr et al. 2018). The two studies that focus on cancer in young adulthood (Parsons et al. 2008; Grinyer 2009) will be examined in the following section on young adults with cancer.

A central theme in this literature is how cancer diagnosis and treatment reconfigure identities, causing both positive and negative implications (Kerr et al. 2018). Several of these studies examine cancer using Bury's (1982) "biographical disruption" to gauge how people respond and adapt to cancer. For example, using interviews and participants' photographs, Balmer, Griffiths, and Dunn (2015) apply the biographical disruption framework to individuals living with poor prognostic cancers. Balmer et al. (2015) find that for poor prognostic cancers, full recovery is impossible and "threaten[s] biographical trajectory and self-identity forever." Others show how cancer disrupts day-



to-day life, requiring one to reevaluate future goals, expectations, and self-concept (Reeve et al. 2010; Sinding and Wiernikowski 2008; Brown and de Graaf 2013; Rozmovits and Ziebland 2004). These studies do not specify a specific life course stage, opting for samples that are heterogeneous by age.

Others have documented the enduring experiences of uncertainty and worry as cancer survivors live in "the remission society," or the space between healthy and sick (Frank 2005, 2013). This literature shows that cancer is not experienced as an acute disease (Fosket 2000; Frank 2005, 2013). At the conclusion of active treatment, individuals experience continued medical surveillance and experience enduring fears of recurrence (Quigley 1989; McKenzie and Couch 2004). Despite remaining preoccupied with the possibility of disease and untimely death, cancer survivors feel pressure to hide cancer's ongoing effects on their everyday life (Sinding and Gray 2005; McKenzie and Couch 2004; Little, Jordens, and Sayers 2000). As such, "survivors are required to act as if cancer is over, and at the same time they are required to act to prevent recurrence. The first requirement rejects or pathologizes an ongoing sense of vulnerability to cancer; the latter is premised on it" (Sinding and Gray 2005:157).

Sociological inquiry has also been extended to examine cancer culture and dominant narratives of cancer survivorship. Youll and Meekosha (2011) demonstrate that "positive thinking" in response to cancer serves to minimize stress and harm while also reinforcing dominant neoliberal ideals of personal responsibility. Similarly, Bell (2012) shows how discourses frame cancer survivorship as an opportunity for "post-traumatic growth" and a "unique opportunity to catalyze the patient's physical and psychological development" (Bell 2012: 584). Bell (2012) shows how oncological discourses on cancer

survivorship reflect the neoliberal logic of privatized risk management, where the individual is expected to take responsibility for managing the risk of cancer recurrence to alleviate the financial burden on the healthcare system.

### *Young Adults with Cancer*

The bulk of prior scholarship on young adults with cancer occurs in oncology, nursing, psychology, and social work. Often this scholarship uses quantitative methods and applies a cross-sectional design to provide insight into the impact of cancer on work (Parsons et al. 2012; Yanez et al. 2013), family formation (Kirchhoff et al. 2012; Xie et al. 2022; Bellizzi et al. 2012), financial hardship (Lu et al. 2021), sexual function (Cherven et al. 2021), psychological wellbeing (Vandraas et al. 2021; Odo and Potter 2009). Other studies generally serve to identify “unmet needs” and “special considerations” of the young adult population (Joffe et al 2022; Choi, Becker, and Kim 2022).

A central theme in the literature has been the impact of cancer on vocational activities and paid employment. Studies show that while young adults return to work after cancer treatment, productivity can be negatively impacted by the long-term physical or cognitive side effects of treatment which reduces earnings and causes distress (Stone et al. 2017). Exploring the impact of cancer on work and education for adolescents and young adults, Parsons et al. (2012) find that although three-quarters of young adults had returned to work or school 15-35 months after diagnosis, more than 50% had trouble with cognition (Parsons et al. 2012).

This literature also examines the impact of young adults (hereafter YA) cancer on family formation. Fertility is cited as a central concern for young adults, particularly after

the conclusion of active treatment (Xie et al. 2022). Kirchhoff et al. (2012) compare marriage and divorce among young adult cancer survivors (20-39) with controls who did not have cancer. They find that, when compared with controls, cancer survivors were less likely to be married (58% vs. 64%) and had an increased risk of divorce or separation (18% vs. 10%).

Literature in social work, psychology, and nursing often emphasize the impact of cancer on young adult psychological wellbeing. Studies identify isolation, uncertainty (Odo and Potter 2009), and fear of recurrence (Vandraas et al. 2021) as central barriers. A central theme across this literature is that cancer has the potential to foster personal development and post-traumatic growth (Bellizzi et al. 2012; Parsons et al. 2008). As such, studies often conclude with purposed remedies to diminish maladaptation after illness (Bellizzi et al. 2012; Bellizzi and Blank 2006).

Few studies examine young adult cancer using qualitative methods. Parsons et al. (2008) conceptualize three forms of intricately interwoven “work” for young adults (16-35) with bone cancer while in active treatment: illness work, identity work, and vocational work. In examining illness narratives, Parsons et al. (2008) found that illness was a transformative experience that changed how young adults approached vocational labor. This transformation repositioned young adults socially, psychologically, and physically; young adults did not “go back” but re-entered work activities from a different perspective (Parsons et al. 2008).

Medical sociologist, Grinyer (2009), examines life after cancer in adolescents and young adults (diagnosed between the ages of 14 and 26) in the United Kingdom, examining themes of loss of independence, disruption to life trajectories, and the effect of

illness on appearance, fertility and sexuality, and changes to personal philosophy. While this work serves as an important starting point of sociological inquiry into the experiences of cancer in young adults, Grinyer (2009) fails to address the role of the National Health Service in shaping illness experiences. Unlike the findings of this dissertation, the participants in Grinyer's (2009) study did not describe difficulty accessing treatment, fear of a loss of health insurance, or the high cost of care due to un- or under-insurance. While participants in the UK did describe long-term financial consequences of cancer, they were attributed to side effects, comorbidities, and disabilities, rather than financial toxicity, which, because of the *cost* of access to healthcare, pattern future employment, relationships, and family-formations. By examining the experience of illness in the context of employer based-healthcare and less-robust social safety nets, this study illuminates the ways in which structural conditions shape illness experience and how young adults without guaranteed access to healthcare mobilize resources to address gaps in institutional support.

### *Body and Embodiment*

Embodiment is central to our sense of being, who we think we are, and what others attribute to us (Waskul and van der Riet 2002). In cases of chronic illness, the relationship between the self and the body is disrupted, as is the taken-for-granted assumption that our body will function as we would like (Kelly and Field 1996). While the examination of chronic illness often neglects the body, the experience of living with a chronic illness is “inescapably embodied” (Toombs 1992: 134), and the sociology of health and illness has paid increasing attention to embodiment (Williams 1996; Corbin 2003). Such perspectives hold that chronic illness challenges taken-for-granted

embodiment, resulting in dys-embodiment, and that re-embodiment takes considerable biographical work (Williams 1996). Cancer causes changes to bodies. For a diagnosis to occur, individuals and medical systems must *symptomize* bodily sensations (Brandner et al. 2014). Or, said differently, an individual must interpret an unexplained physical sensation as a potential symptom of illness (Anderson, Cacioppo, and Roberts 1995; Anderson et al. 2010; Hay 2008). Embodiment is central to the experience of bodily sensations. As asserted by Hays (2008:221), “a sensation is embodied; it is felt experience. By contrast, a symptom is a constructed and socially informed cognitive interpretation that indexes but is not itself an embodied sensation.” Diagnosis includes numerous visits to physicians and diagnostic testing, where bodies are examined, scanned, and biopsied. Treatment often subjects the body to surgery, chemo-, and/or radiation therapy, with profound implications for how bodies feel, function, and appear. While some of the outward marks on bodies may diminish with time, as hair returns with the conclusion of chemotherapy, others endure, and bodies may carry forward scars from surgery, tattoos from radiation, and chronic fatigue and pain.

Prior literature illuminates the embodied experience of cancer. Horlick-Jones (2011) centers his experience of breast cancer to examine how fears of anxiety and recurrence disrupt “everyday health competence” in the interpretation of “normal” bodily sensations. Blaxter (2009) describes how medical technology results in patient alienation and disembodiment. Other literature has examined the impact of cancer treatment on bodies, typically focusing on issues of gender and sexuality (See: Jain 2013). Focusing on the influence of age and life course stage in interpretations of bodily sensations, Brandner et al. (2014) illuminate how physical sensations associated with ovarian cancer are

interpreted based on factors like aging and menopause. While these provide essential insight, studies have yet to examine how age and life course stage shape the embodied experience of cancer in young adulthood.

In contemporary society, youth and youthful bodies are associated with health. In young adulthood, societal expectations assume individuals and their bodies to be at their peak in terms of health, fitness, attractiveness, and productivity. Such narratives are disseminated through media and advertisements that associate youth with health and beauty (Dittmar 2011). This project contributes to conversations within the sociology of the body and embodiment by focusing on the lived meanings and experiences of young bodies with cancer, a population that challenges the societal assumptions associated with youth and health. Importantly, these assumptions not only impact an individual's perception of their body but also how bodies are coded by health care providers. As young adults experience high rates of delayed diagnosis, findings can provide insight into the experience of young bodies as they seek out medical intervention.

### *Intersectionality*

In the 1960s, 70s, and 80s, the heuristic term 'intersectionality' was used to draw attention to the mutually constitutive forces of race, class, gender, sexuality, and disability (Crenshaw 1991; Collins 2000). Central to the origin of intersectionality were Black and Brown women whose experience was erased in the political and legal dialogues of Civil Rights and feminist movements organized around unitary issues and essential and universal experiences of 'sexism' or 'racism.' Social categories on the micro level correspond with interlocking systems of privilege and oppression on the macro level to produce health disparities (Bowleg 2012). These experiences of elitism and racism in

the mainstream feminist movement caused Black women to form Black feminist groups and community organizations like the National Black Feminist Organization (See: Combahee River Collective 1977). During the 1980s and 1990s, the themes of intersectionality were introduced into academia by scholarly activists situated in interdisciplinary programs (hooks 1981; Lorde 2012). Often, Kimberle Crenshaw is cited as the introducer of intersectionality in academic and legal conversations. In “Mapping the Margins,” Crenshaw (1991) discusses the limitations of identity politics to transcend difference, arguing that it “ignores intergroup difference.” Using violence against women of color as an example, Crenshaw demonstrates the inability of advocacy and social movements organizing around violence against women to capture the vulnerability of women of color. Instead, she argues that these movements construct identities as either/or, a woman either/or person of color, marginalizing the experiences of women of color “to a location that resists telling” (Crenshaw 1991:1241).

Intersectional analysis marks a significant movement away from additive approaches to social inequality that assume experiences are independent, separate, and summative and that identities and oppressions can be ranked (Bowleg 2008). Intersectionality conceptualizes the relationship between age, race, class, gender, and other axes of power as interlocking categories that are socially constructed, interdependent, mutually constituted, and relational (Collins 2000; Crenshaw 1991; Zinn and Dill 1996). The benefits of intersectional approaches in examinations of the experience of young adults with cancer are reinforced by Bowleg (2012:1270), who summarizes the three central tenants of intersectionality: (1) “social identities are not independent and unidimensional but multiple and intersecting, (2) individuals from

multiple historically oppressed and marginalized groups are the focal and starting point, and (3) multiple social identities at the micro level intersect with macro-level structural factors to produce health disparities.” The main contribution of this work is emphasizing age as an axis that shapes social relations and individual experiences.

Race, ethnicity, and gender are central to the story of cancer, impacting the organization and evolution of cancer awareness and the “war on cancer” (Wailoo 2010:6). Early cancer awareness campaigns highlighted the vulnerability of white middle and upper-class women. These campaigns utilized “intensely individualized in personal experience,” focusing on images of femininity, domesticity, and motherhood. Reinscribing the racial hierarchy, medical systems assumed that cancer was a disease of the civilized and that “primitive” African Americans were immune to the disease. Only when African Americans migrated from primitivism to the urban north would they be susceptible to cancer. Until the 1960s, white women remained at the epicenter of cancer awareness, anxiety, and visibility in the United States. The implication of the cultural narrative depicting cancer as a disease of white, class-privileged women continues to be apparent. In the 1960s, patients, scholars, and activists began focusing on the experience of Black women, fueled by the cancer establishment and public criticism. In the 1980s and 90s, cancer awareness moved from a private to a public experience, focusing on fundraising events, ribbons, and dedicated awareness months (Wailoo 2010). Presently, gender and racial politics continue to shape cancer experiences, awareness, and disparities, reinforcing the necessity of intersectional approaches in examining the illness experiences of young adults.

### **My relationship to Young Adult Cancer**



I approach this project as the partner of a young adult with cancer. My partner, Zach, was diagnosed with advanced-stage Hodgkin's Lymphoma in 2016. I offer my positionality with the recognition that my perspective is biased. I do not think anyone who has held a loved one's hand through cancer treatment emerges unimpacted by the experience. This experience sparked curiosity around the ways in which illness experience varied by age and life course stage and inspired this project. Numerous sociologists have used their illness experiences to recover their voices and find meaning. In this dissertation, I undertake a similar project. To find myself in the enduring disruption caused by illness and to illuminate the structures that shape experiences based on age.

## **Methods**

### *Research Design*

This dissertation investigates cancer during the young adult life stage. I employ a qualitative research design suitable to gain depth and nuance regarding young adults' lived experiences of off-time illness. This study relies on semi-structured, in-depth interviews with young adults with cancer, participant observations of young adult-support and advocacy organizations, and content analysis of publicly available information. The research design began with observations and interviews at a national young adult cancer organization. In-depth interviews continued, including young adults with and without involvement in YA support and advocacy. This dissertation incorporates aspects of intensive interviewing and participant observation. This allows for an in-depth exploration of the experience of cancer in young adulthood (Lofland and Lofland 1984; Emerson 2001). This exploratory study does not aim for generalizability. Instead, the

small sample size, which is not nationally representative, allows for an in-depth examination of young adults' lived experiences.

### *Target Population and Recruitment*

I sought to interview young adults diagnosed with cancer between 18-39. The range of 18-39 reflects how the population of young adults with cancer is defined by both the medical literature and cancer organizations. I located my research across the United States due to the specialized nature of the population. While more than 80,000 young adults are diagnosed with cancer every year, the population is geographically dispersed and isolated, making it difficult to contain the research on one specific region. Therefore, I did not restrict the sample based on a young adult's specific cancer diagnosis. To draw a sample of self-identified young adults with cancer, I used purposive sampling, recruiting interviewees through young adult-support groups, YA advocates and ambassadors. I first identified potential interviewees at young adult support and advocacy events. I found young adults eager to discuss my research, their experiences, and invite me to join them in subsequent convention events. I attribute this overwhelming interest in participation to the isolation experienced by the young adult with cancer and recognition of the lack of research, support, and resources for young adults with cancer. Employing theoretical sampling, I used these national conventions as the foundation for my snowball sampling. The individuals I met and interviewed at national conventions would pass my contact information to other members of the young adult community, either through in-person and online support groups or directly to contacts. My positionality as a young adult cancer caregiver likely facilitated access to interviews. As a result, young adults treated me as an insider, someone who could relate to the unique obstacles experienced as a

young adult with cancer. Participant observations of national young adult cancer support and advocacy groups continued throughout the period of data collection.

### *Data Collection*

My formal participant observation occurred over two years at national and regional young adult cancer support and advocacy events. I wrote quick “jottings” in the field and recorded extensive written notes after leaving the field. Data also included content analysis of publicly available materials circulated by young adult cancer organizations, including webpages, blog posts, exhibition material, videos, and podcast transcriptions. Interviews were conducted between March 2018 and August 2022. Thirty-five of the interviews occurred prior to February 2020. Five interviews were conducted summer of 2022 to gauge a preliminary understanding of the impacts of the Covid-19 pandemic on young adult experiences. Interviews lasted one hour to three hours. In some cases, young adults were interviewed on multiple occasions. Interviews that were conducted at young-adult support and advocacy events and were conducted in-person. Others were conducted in-person or by phone or videoconference, depending on the location and preference of the young adult. After each interview, I recorded notes about my initial impressions of the interview, including notable moments and rapport. I wrote memos throughout the data collection process to flesh out emergent themes. Interviews were recorded and transcribed verbatim. Interviewees were assigned pseudonyms, and identifying information was removed. Interviews and field note transcriptions were then uploaded to Dedoose, a qualitative data analysis software program.

### *Data Analysis*

This dissertation employs a modified grounded theory approach (Glaser and Strauss 1967; Strauss 1987). Grounded theory provides a flexible and inductive analysis method in which themes emerge from the data (Charmaz 2006). I incorporated several of the defining components of grounded theory in my data analysis, including sampling toward theory construction, intensive interviewing, simultaneous data collection and analysis, constructing codes from the data (open coding), analytic memo-writing, and theoretical sampling (Charmaz 2006:5-6).

The qualitative data analysis software Dedoose was used to code interviews based on themes, events, and experiences. In my initial coding practice, I utilized open coding to analyze the transcripts and identify emergent themes. This allowed me to construct codes that fit participants' experiences and develop an analytic framework to make visible relationships between implicit processes and structures (Charmaz 2006: 54). As coding continued, the coding framework was refined and updated. I combed through the data for patterns between young adults' lived experiences, paying particular attention to similarities and differences across race, class, and gender. I engaged in analytic memo-writing throughout the coding process to elaborate categories, define relationships, and identify gaps (Charmaz 2006). I used both open coding and codes informed by the literature to identify core themes. Core themes included diagnosis, treatment, disruptions, and responses to cancer. These core themes inform my four empirical chapters.

### *Study Participants*

Study participants included 40 young adults. Young adults had been diagnosed with a wide variety of cancers. The two most common cancer types were blood cancer

(14) and colorectal cancer (10), each making up about one-quarter of the young adult diagnoses. The next most common cancer type was breast (5). Diagnoses also included gynecological, soft tissue sarcoma, melanoma, thyroid, and brain cancer. Two young adults were diagnosed with a second primary cancer that likely resulted from treatment of the first primary cancer. Over half of young adults were diagnosed with advanced-stage cancer, with one eighth having metastatic disease<sup>4</sup>. Around one-third of young adults had experienced a cancer recurrence. Time since first primary cancer diagnosis spanned from seven months to 19 years.

A little over half of young adults were white, with 18 BIPOC (Black, Indigenous, People of Color) young adults included in the sample. The majority of the sample is female identified (27 women, 13 men). The majority of young adults were middle class by education and pre-diagnosis occupation, although not all young adults had returned to their pre-diagnosis employment. The precarious position of young adults challenged traditional metrics of social class as some young adults remained asset-poor to maintain Medicaid eligibility. Young adults' ages ranged from 18 – 43. The outlier by age (43) had been diagnosed with a first primary cancer at 28 and a second primary cancer at 42. Around one-half of young adults were partners, and a quarter were parents. Thirty-nine young adults lived in the United States, and one lived in southern Canada.

Young adults received various treatment regimes, including oral and intravenous chemotherapy, radiation, surgery, and immunotherapy. Two young adults were participants in clinical trials. All but three young adults had either private or public health

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<sup>4</sup> There is variation on how cancer is staged. Most solid-tumor cancers are staged based on size and spread of tumors. In the case leukemia which originates in the bone marrow, staging varies based on subtypes and is not captured in the language of “advanced stage” and “metastatic disease.”

insurance when they sought care for unexplained bodily sensations. All three uninsured young adults lived in states that expanded Medicaid Presumptive Eligibility, allowing hospitals to enroll eligible young adults with temporary Medicaid coverage at first contact with the medical system.

### *Chapter Outlines*

In chapter two, I examine how young adults experience cancer diagnosis. Young adults experience diagnosis as a multi-sited process encompassing self-diagnosis and professional diagnosis. A central theme in these accounts was the difficulty navigating the age-specific construction of young adulthood as a period of health and cancer as a disease of old age. Such constructions were especially salient with cancer symptoms that were less culturally recognized, a byproduct of cancer-specific and symptom-specific awareness campaigns. Young adult accounts of self-diagnosis began with a description of when and how unexplained bodily sensations (that would be retrospectively defined as symptoms of cancer) were first interpreted, explained, and acted upon. Self-diagnosis was impacted by how cancer symptoms presented in the body. Young adults that identified a lump/swelling as part of the self-diagnosis process were likely to identify this bodily sensation as abnormal and seek a professional medical consultation. Those young adults that experienced lesser-recognized cancer symptoms were likely to contain symptoms with explanations based on age-based assumptions of health, biography, and lifestyle choices. In some cases, cancer symptoms were not only contained by lifestyle choices but also explained by them. The case of colorectal cancer demonstrates the social construction of cancer awareness, the stigma of certain parts of the body and the lack of awareness of colorectal cancer symptoms, both exacerbated by life course stage, meant

that symptoms were contained until they were significantly disruptive to everyday activities.

This chapter also explored the experience of professional diagnosis or all engagement with the medical system that came before the diagnosis event. Most young adults experienced what they considered to be a delayed or under/misdiagnosis (hereafter misdiagnosis). Misdiagnosis was more likely to occur when young adults did not experience the most recognized cancer symptoms: a lump and/or swelling. The dominant perception, expressed almost universally by young adults that experienced a delay in professional diagnosis, was that seeking-help behaviors were met with a lack of concern by doctors and healthcare providers. Reasons for this perceived lack of concern included age-based assumptions of health, a lack of social power, and gendered and racial stereotypes. For young adults with health care capital, access to medical networks helped override age-based lack of concern by providing informal consultations, assisted navigation of healthcare institutions, and personal referrals.

Chapter three draws attention to the experience of the body for young adults with cancer, focusing on the experience of aberration or out of placeness. Aberration represents both the embodied experience of the young adult patient and the positionality of a young adult patient in medical knowledge. This chapter emphasizes the role of the institutional environment in shaping the young adult experience of aberration. I conceptualize “cancer treatment” as an institutionalized space in-which young adults experience aberration in the physical space and medical practice. I describe how the consequence of this aberration contributes to a loss of agency for young adult bodies. My findings also suggest variations exist in the experience and consequences of aberration

based on race, class, and gender. I conclude with an in-depth discussion of one particularly salient consequence of aberration: loss of reproductive autonomy.

Chapter four explores the impact of a cancer diagnosis on education, occupation, and family formations. Cancer in young adulthood resulted in the disruption of educational and occupational activities. To cope with the side effects and time commitment of treatment, young adults reduced hours, went on leave or disability, or withdrew entirely. The timing of this disruption during young adulthood meant that many respondents were at the onset or upswing of their professional lives, resulting in potentially long-term, cascading impacts. Key concerns included loss of income, workplace discrimination, loss of previously held positions, and the impact of long-term effects and late effects on work performance. Some young adults on the brink of their professional careers maintained the same long-term goals despite obstacles, while others reframed disrupted plans as opportunities to transition into something better. Health care policy exacerbated disruptions to work-related activities. Those young adults that had access to supplemental insurance and long-term disability benefits or received insurance through a parent's and or partner's health insurance were more able to navigate disruptions. The Affordable Care Act's Medicaid expansion and Presumptive Medicaid Eligibility were vital in improving access to healthcare for low-income, uninsured young adults. At the same time, Medicaid's income restrictions postponed a return to the workforce. The need for future treatment and long-term follow-up care meant that access to benefits like paid time off and health insurance was central to all future employment decisions.



Cancer in young adulthood disrupted family formation, friendships, and relationships with parents, partners, children, and sexual partners. In response to the disruption of work and education, young adults moved home or accepted parental financial support, challenging expectations of independence in adulthood. Young adults described a universal strain on romantic relationships due to caregiving, side effects of treatment, changes to sexual functioning, and financial strain, including relationships established before diagnosis, during and after treatment, and the disruption of future relationships. Young adults also described feeling “left behind” by friends as peers progressed through life without illness-related disruptions, long-established friendships were dissolved, and new friendships were fostered through the formation of social networks based on the shared experience of cancer in young adulthood. Minimal public support in the experience of catastrophic illness during young adulthood exacerbated disruptions. Lacking robust savings and assets, and often burdened with student loan debt, even those young adults with class privilege had difficulty navigating the economic uncertainty and financial strain associated with the disruption of work-related activities, high healthcare costs, and future economic uncertainty. Family “filled the gaps” in social welfare programs, providing instrumental and financial support and caregiving for young adults and child dependents. Upper and middle-class families were more likely to provide young adults with direct financial support. In contrast, working-class families provided care, provided meals, and organized community fundraisers to support young adults.

My final empirical chapter explores the strategies of action young adults employ in life post-cancer diagnosis. These strategies of action are crafted with common sense narratives and ideologies, or “chunks of culture” (Swidler 1986). Key strategies of action

identified include bodily labor, family work, and support work. Young adults respond to diminishing contact with the medical system and uncertainty in health status with bodily labor to limit, prevent, and/or identify any disease progression or recurrence. Bodily labor was encouraged by oncology clinicians and young adult cancer organizations, placing the burden of disease detection and prevention and long-term follow-up care on individual young adults. This reflects the privatization of risk management, where the individual young adult manages the risk of cancer progression or recurrence through individual (lifestyle) choices, alleviating the burden placed on medical institutions. Women with long-term partners and children respond to the pressure of intensive mothering by emphasizing the importance of family work, reflecting the disruption of the traditional roles of caregiver and nurturer. Finally, finding themselves outside of existing support systems, some young adults labor to facilitate their own resilience with support work. Support work included involvement in peer-to-peer support and advocacy work related to the needs of a specific cancer community. Support work involved vast emotional labor and often reflected the needs of those with race and class privilege. In centering the importance of age, support spaces often assumed a monolithic standpoint of whiteness, with BIPOC community members existing, rhetorically and physically, on the periphery of support spaces. In response, BIPOC young adults focused support work on issues of importance to their communities.

Finally, I conclude the dissertation by returning to the central research questions and discussing the theoretical and practical implications of this project for the field of sociology and medical institutions.

## CHAPTER II

### “NO ONE TOOK ME SERIOUSLY”: AGE-RELATED BLINDSPOTS IN DIAGNOSIS

*In the summer, I was feeling a little off. I wasn't feeling like myself. I couldn't really pinpoint why, it was never anything major. I just felt a little low on energy...I was at work [as a monitor] at my apartment complex's pool when I threw out my lower back. I almost fell to the floor, but luckily my mom was there ... and [she] helped me like get back on my feet and at least walk on both feet, because I was really in a lot of pain. I could barely stand up.*

*I woke up the next morning and obviously my back was still hurting, but there was another pain that was slowly developing...I was getting a sharp pain in my lower abdomen. It was kind of in my stomach region but it wasn't in my stomach. It was just in that lower left abdomen. And the pain started to grow over the next few weeks. My stomach, up my chest, and then it wrapped around my left shoulder and it was just sharp, continuously sharp stabbing pain.*

*Because of this sharp, stabbing pain, I started eating less. It got to the point where I was barely eating anything every day. Like, I would eat like a saltine cracker, and I would be really full.*

*I went to the hospital twice because of the pain, and the hospital didn't help me at all. They thought I was having stomach pains and wanted me to take over-the-counter medication for stomach issues, and I knew that it wasn't my stomach. They would have me do stretches to see where the pain was, the sharp stabbing pain. They would make me stretch my arm, my neck, and my back. They kept asking me if it hurt, and I would say no, every time. It felt something more internal. I saw two different physicians on two different occasions, and they didn't help me at all. Neither of them suggested for me to get blood work. That's a normal, routine thing that people get at hospitals; at least, that's what I thought. But all they had me do was do stretches and take over-the-counter pain medication. At the point when I'm on my complete death bed, that's when I was diagnosed, and that same day, within the hour, they requested an ambulance for me to be taken to a [larger hospital], about 30 minutes away and then they started treatment right away. Hector, 19, Latinx, blood. Diagnosed at 18.*

In exploring diagnosis stories like Hector's, I struggled to reconcile young adults' perspectives and experiences with medical understandings of "diagnosis." From a medical perspective, diagnosis is a single-realization event where a clinician presents a patient with definitive news. Young adults, however, described diagnosis as a

longitudinal process (Schaepe 2011; Blaxter 1978). Diagnosis stories began when young adults retroactively perceived their first abnormal bodily sensations were identified, regardless of their first interpretation. They then focused on interactions with the medical system prior to the diagnosis event: help-seeking, patient-clinician interactions, and diagnostic testing. Ultimately, the diagnosis event was treated more as the conclusion to the often-complicated process. Central to these accounts was the difficulty navigating the age-specific construction of young adulthood as a period of health and cancer as a disease of old age. The expectation of ill-health in older adulthood shaped individual bodily sensation interpretation and as well as informal and formal interactions with the medical system. Such constructions were especially salient with cancer symptoms that were less culturally recognized, a byproduct of cancer-specific and symptom-specific awareness campaigns. The data provided by these stories grant a unique opportunity to examine how young adults view their age as central to their understanding of their bodies, interactions with the medical system, and experiences as patients, forecasting the creation of young-adult-specific cancer communities.

This chapter examines the diagnosis experiences of cancer in young adulthood. A central finding that emerged during in-depth interviews and participant observations was the centrality of age in navigating symptom interpretation and professional diagnosis. Focusing on diagnosis, this chapter asks the questions: 1) what are the embodied experiences of self-diagnosis? and 2) what are the experiences of professional diagnosis? Young adulthood is socially constructed as a period of health, and cancer as a disease of old age. Such assumptions shape how individuals and medical systems interpret young adult bodies. I offer the term “age-related blind spot” as a conceptual tool to capture how

age-based expectations of health function to make young adults, clinicians, and medical systems slow to recognize ill health.

Contemporary society associates youth and youthful bodies with health and cancer as a disease of old age, creating "age-related blind spots" where young adults, clinicians, and medical systems are slow to recognize ill health in some young adult bodies. In young adulthood, societal expectations assume individuals and bodies are at peak health, fitness, attractiveness, and productivity. At the same time, dominant ideologies view later life course stages with inevitable biological decline and frailty (Salter and Salter 2018). Such ideologies buttress expectations of cancer as a disease of old age. While 60 percent of cancers occur in people over 65, cancer can and does occur at any age. Further, recent trends illustrate increasing incidences of cancer in younger bodies. This sociocultural construction of young adulthood as a life stage of health and assumptions of cancer as a disease of old-age shapes an individual's perception of their own body sensations – and if they are contained – and how an individual perceives their bodily sensations to be interpreted by health care providers. Sociocultural expectations attached to life course stage are reflected in, and codified by, institutional policies and practices that use *age* to informally and formally understand risk and administer diagnostic testing. My findings show that the simultaneous assumptions of health in young adulthood and cultural construction of cancer as a disease of old-age impact perception of cancer risk and symptom interpretation by individuals and health care providers and shape institutional policies and practices, leading to age-related blind spots for individuals, and bodies, that fall outside of societal expectations.

Prior sociological research on diagnosis suggests that diagnosis is both an official category and the process in which that label is applied (Blaxter 1978; Jutel 2009; Jutel and Nettleton 2011). Healthcare practitioners utilize classifications of diseases (nosologies), taxonomies, and other authoritative classification systems for diagnostic guidance (Jutel and Nettleton 2011). Such classification systems emerge from biopower, population management, and the growth of statistics (see: biopower). As a process, diagnosis occurs when an individual presents symptoms to a healthcare clinician with diagnostic authority. The healthcare clinician will examine the patient, assess the evidence, and diagnose their symptoms (Jutel and Nettleton 2011).

Biomedicalization and the increasing use of clinical risk assessment have resulted in pre-disease identification via medical screenings (Salter et al. 2011). Armstrong and Eboralla (2012: 162) define medical screening as “the purposeful application of tests to an asymptomatic population in order to classify people into those who are unlikely to have or develop a disease and those who are likely to have or develop a disease.” Age-based expectations are central to the application of risk assessment, as age is central to characterizing “risk” and medical screenings and age is used as a criterium for eligibility. For example, Salter et al. (2011:808) argue that “screening for osteoporosis and assessment of fracture risk can be understood as a process of biomedicalization of aging and bone health.” In the case of cancer, one can assume that risk assessments and medical screenings that reinscribe age-based ideologies of ill-health in older adulthood frame not only who is at risk but also who is outside of risk of cancer.

Before the diagnosis process can begin, an individual must *symptomate* bodily sensations (Brandner et al. 2014). Or, said differently, an individual must interpret an

unexplained bodily sensation as a potential symptom of illness (Anderson et al. 1995, Anderson 2010). Studies examining patient delay in help-seeking demonstrate the complexities of identifying bodily sensations as symptoms of illness (Andersen et al. 2010, Locock et al. 2016). Sensations may be "contained" or normalized based on social situations, life biographies and expectations, and cultural values and explanations (Anderson et al. 2010). In the case of cancer, which often has mild or moderate symptoms in the early stages, individuals experience uncertainty in defining "what counts" as a symptom of cancer is more present among unspecific, vague, or diffuse illness complaints (Anderson et al. 2015). The influence of age and life course stage in the interpretation of abnormal bodily sensations is shown by Brandner et al. (2014), who find that ovarian cancer is interpreted in reference to factors like aging and menopause.

Previous research on lay accounts of diagnosis finds that patients experience diagnosis as a "journey" (Beach 2009; Leydon, Bynoe & Sutherland, and Coleman 2003) or "longitudinal, multi-sited search process that culminates in a realization event" (Schaepe 2011:912). For example, analyzing 138 written cancer diagnosis narratives of recently diagnosed patients, Salander (2002) finds that patient narratives spanned from first contact with clinicians to the conclusion of treatment. Salander (2002:721) argues that, for the patient, the "bad news" of diagnosis "reflects the process of being diseased by cancer, and how medical services are available when one is in need of establishing a helpful relationship." The quality of contact with the medical system prior to the formal diagnosis event impacts patient opinions of doctors and expectations of future care (Schaepe 2011; Leydon et al. 2003). For example, in examining the experiences of diagnosis with blood cancer, Schaepe (2011) finds that patients' and caregivers'

experiences prior to diagnosis impact how the diagnosis is internalized as "good news" or "bad news." Organizational arrangements, delays, and issues with care coordination lead to positive and negative associations with providers and the medical system (Schaepe 2011).

Patient-provider interactions are not free from health inequity. To address this gap, Shim (2010) offers the term “cultural health capital” to account for how patient-provider interactions unfold in ways that may generate disparities in health care, including delays. Cultural health capital is defined as “the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviors, and interactional styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal health care relationships (Shim 2010).

This chapter uses a narrative approach to examine the longitudinal process of diagnosis, or what I characterize as the “diagnosis stories” of young adults. This study fills a gap by interrogating lay-perspectives on the diagnostic experiences of cancer generally and the case of young adults specifically and intervenes with empirical evidence to disrupt cultural assumptions around age and illness. While existing literature examines the processes of symptom interpretation and patient-provider interactions as separate parts of the illness experience, the narratives provided by young adults challenges this divorce. In this chapter, I examine these experiences of diagnosis in the way young adults articulate them: as part of the same diagnostic process. In connecting these sites, we recognize that individuals, healthcare professionals, and medical systems do not exist in isolation. Instead, they are embedded within the same sociocultural contexts as the individual body. As such, sociocultural context also impacts how



healthcare providers and medical systems explain, interpret, and act upon the bodily sensations of young adults.

First, I examine the embodied experience of self-diagnosis and symptom interpretation. I then examine experiences of professional diagnosis, focusing on patient-provider interactions. Next, I pay particular attention to how the institutional environment contributes to age-related obstacles to a successful cancer diagnosis in young adult bodies. Finally, I discuss core findings, relationship to prior research, and broader implications.

### **Young Adult Diagnosis Stories**

The diagnosis stories of young adults were recounted as a narrative. They did not focus on only the event of diagnosis or the moment a diagnosis was given; rather, diagnosis stories spanned the events before and after diagnosis was received. Diagnosis stories followed a similar pattern and were recounted as two sub-topics: First, the embodied experience of self-diagnosis, or when abnormal bodily sensations were discovered, how they were interpreted, and acted upon. Second, the embodied experience of professional diagnosis, or patient-provider interactions leading up to the moment the diagnosis was given. For young adults, diagnosis was articulated as a longitudinal process with emphasis placed on the experience of symptom interpretation up to the diagnosis event rather than the event itself. A common theme throughout most chapters of diagnosis stories was the perceived centrality of age in shaping a young-adult-specific diagnosis story. To capture this centrality of age, I offer the term "age-related blindspots," where young adults, clinicians, and medical systems are slow to recognize ill health in some young adult bodies, as a conceptual tool to frame their diagnosis stories.

## **Embodied Experience of Symptom-Interpretation**

When asked about their diagnosis experience, young adults' narratives began with a retrospective discussion of the first perceived abnormal bodily sensation. These descriptions highlighted the social construction of widespread awareness around certain types of cancers and certain symptoms of cancers. The elevation and circulation of cancer and symptom-specific knowledge make individuals readily *see* and *address* such symptoms. Such awareness makes young adults more likely to disrupt biographical containment (based on age and expectation of health) to interpret well-known cancer symptoms as abnormal and requiring medical attention. In the following section, I examine this process of self-diagnosis, highlighting how the physical presentation of some cancers, resulting from commonly recognized cancer symptoms, is protective against age-related assumptions of health that permeate cultural understandings. Finally, I continue with the experience of young adults with lesser-known cancer symptoms who emphasized the role of age and assumptions of health in the interpretation, and containment, of their unexplained bodily sensations. Before beginning this discussion, I briefly address the variation in the bodily presentations of cancer symptoms.

The bodily sensations associated with cancer are varied, reflecting the diversity within the group of diseases understood as “cancer” and variations in the presentation of “cancer symptoms.” In this dissertation, the term “cancer” is used to describe various illnesses, including colorectal cancer, testicular cancer, acute lymphoblastic leukemia, Hodgkin's lymphoma, anaplastic large cell lymphoma, breast cancer, gynecological cancers, and sarcoma. While all these diseases are “cancers,” their symptoms manifest in diverse ways and are experienced differently by different people. The same cancer,

diagnosed at the same stage, can have a different embodied presentation. The most commonly recognized cancer symptom is an unexplained lump (a hard tissue mass) or swelling. Not all cancers present as such. In the early stages, cancer symptoms are usually mild or nonexistent and have little or no impact on daily functioning, and may not be recognized as signs of cancer and thus become a barrier to care (Al-Azri et al. 2016). When they occur, lumps/swelling are often associated with a later stage of disease and may not be 'obvious' to a patient.

### *Commonly Recognized Cancer Symptoms*

Widespread awareness of certain types of cancer and certain types of cancer symptoms meant that young adults who found an unexplained lump were much more likely to identify the symptom as concerning and necessitating medical consultation. This bodily sensation occurred in young adults diagnosed with breast cancer, testicular cancer, and certain lymphomas. In addition, young adults that discovered an unexplained lump/swelling were more likely to interpret this lump/swelling as abnormal and seek medical consultation.

Michael (33, white, testicular) interpreted his non-tender lump as a serious symptom right away. Michael was riding his bicycle when he noticed his abnormal bodily sensation, "my left testicle was as hard as a rock. It was like a golf ball." Despite not having health insurance, Michael went to the hospital the following day for an examination. He credits his immediate action to a social media post emphasizing the potential severity of such an unexplained lump: "I remembered reading an article on Redditt, 'if anything is unusual with your junk, get it checked out immediately because you're either going to be sterile or you're going to have cancer.'" Michael "took [the

article] to heart” and credits this awareness with his positive outcome, asserting that the post “kind of saved my life.” In an interesting reversal, age remains important in this case as young people tend to be more active on social media than older adults and spend more time with media and technology than any other activity (Coyne, Padilla-Walker, and Howard 2013). As such, Michael’s age-related activity of social media use stimulated symptom awareness, counteracting what might otherwise have been a “blind spot.”

The social awareness of lumps/swelling as concerning symptoms also impacted how Donella (41, white, blood) perceived their first unexplained bodily sensation: a lump in the throat. “I had a cold and was feeling around my neck and found what felt like a really swollen lymph node. I thought it was probably related to the cold but decided to wait ‘till I wasn’t sick and if it was still there, I’d go see someone.” After two weeks, Donella had fully recovered from the cold, but the lump remained. Donella recalls being “pretty confident that I had cancer” when scheduling an appointment with their primary care physician to have the lump examined.

Finally, Chloe (34, white, breast) describes “going to the doctor right away” after finding a lump in her breast. Like Michael, Chloe recalls how she “didn’t waste a second” after finding her lump due largely to the cultural awareness associated with breast cancer and the emphasis on self-examination. The cultural dominance of breast cancer awareness was reflected in other young adults whose symptoms included a lump in the breast, reflecting the cultural prominence of breast cancer awareness in North America. Termed “breast cancerization,” this prominence impacts experiences with diagnosis, treatment, and survivorship (Bell 2014). This dominance was reflected in the diagnosis narratives of some non-breast cancer patients, like Heather (31, white, colorectal), who

distinguished cancer symptoms with high cultural visibility, a lump in the breast, and other commonly experienced cancer symptoms, bloody stool. She asserts:

There is a lump in your boob. You go to the doctor, and you go immediately because we're all terrified of what happens is you get breast cancer. I have checked myself in the shower every day of my 31 years of living. I never ever knew that blood in my stool could be cancer.

Heather's experience reflects the pattern among young adults: those with the most-recognized cancer symptoms expressed the need to seek medical care more quickly than young adults with lesser recognized symptoms.

### *Lesser Known Cancer Symptoms*

Young adults with lesser-known cancer symptoms emphasized the role of age-based expectations of health in interpreting abnormal bodily sensations. About three-quarters of young adults experienced lesser recognized cancer symptoms, including changes to bowel movements, bloody stool, fever, fatigue and weakness, loss of weight, dizziness, abnormal vaginal bleeding, and unexplained pain. These symptoms often started as vague or moderate and intensified slowly and occurred in young adults diagnosed with colorectal cancer, gynecological cancers, sarcoma, lymphoma, and leukemia. When experiencing these unexplained bodily sensations, young adults "contained" these symptoms based on individual biography and perceptions of risk (Anderson et al. 2010). In recalling diagnosis stories, these young adults emphasize the role of their age in the interpretation of their unexplained bodily sensations as "normal," particularly in relation to their status as young, healthy individuals.

At age 26, Eric (34, Black, blood) began experiencing "vague" cancer symptoms:

dizziness, bruising on his arms and legs, and fatigue. In recalling his diagnosis story, he emphasizes the role of his age and health in the interpretation of these bodily sensations: “there were all these little warning signs in place and I wrote him off just because I was so young and couldn't really fathom like this was what was going on.” These symptoms were contained based on social situations, biography, and perception of risk. As someone “young and healthy” with an “investment in physical fitness,” Eric did not understand himself as at-risk for a serious illness. As such, his dizziness was attributed to a recent relocation “it's the middle of summer, and I am getting used to the heat and humidity; it's no big deal.”

Cultural perceptions of health in young adulthood led some respondents with vague symptoms to interpret bodily sensations as markers of health rather than symptoms of an illness. For example, Alexis (38, white, colorectal) had recently undergone a career change and was “refocusing on her health” when she began to experience symptoms of colorectal cancer: “I was never like super unhealthy...I've always been active, but like I'd really amped it up the year [before I was diagnosed].” When Alexis began experiencing symptoms of colon cancer, mainly changes in her bowel movements, she attributed them to her recent changes to a healthier lifestyle:

I'd had diet modifications, and I had changes in my stool that I chalked up to eating more fiber, you know, that kind of thing. Sometimes I had constipation, and sometimes I had loose stools, and I was just like, okay, it must be because I'm eating so many more vegetables, you know? I never thought anything else of it.

Here, potential symptoms are contained within Alexis’ biography and her expectation that she is a young and healthy person. While running a 5k, Alexis experienced an

additional symptom, anal leakage: "I kind of shit myself a little bit." Alexis also interpreted this symptoms as a marker of health: running, "Everyone talks about [how] you get like the runner shits, so I was like, well, it's that." After diagnosis, she expressed disbelief that she could have cancer during a period of peak health, "how could this happen?... I was the healthiest I ever was in my life. It was like, wow, you know? I had to go from that to cancer. It was like mind-blowing." Alexis' emphasis on her engagement in health activities demonstrates how cultural explanations related to one's lifestyle choices, like eating healthily and exercising, can also contain potential symptoms (See Anderson et al. 2010). This focus on lifestyle choices as a way to avoid the risk of illness reflects modern society's understanding of health and disease avoidance as a matter of personal responsibility for health, a central component of neoliberal governmentality (Lupton 1994; Ayo 2012; Guthman 2011). Here, age-related blind spots are exacerbated by lifestyle choices that caused Alexis to contain unexplained bodily sensations in the context of health-related activities.

Young adults with colorectal cancer were particularly vulnerable to the containment of symptoms based on an underlying assumption of health in young adulthood, a lack of awareness of the symptoms of colorectal cancer, and the stigma of symptoms deemed "gross." Age is particularly salient here as colorectal cancer rates are increasing in young adults. This supports previous findings that show the median time from symptom onset to treatment as 217 days for young adults compared to 29.5 days for those over 50 (Yarden et al. 2019). This discrepancy was primarily attributed to patient delay in help-seeking and misdiagnosis (the latter of which will be discussed later). As a result, young adults are also more likely to be diagnosed with advanced-stage disease,

with over 70% of young-onset patients diagnosed with either stage III or IV (Yarden et al. 2019). Young adults with colorectal cancer were likely to experience weight loss, abdominal pain, bloody stool, and changes in bowel movements.

Christopher (21, white, colorectal) experienced bloating, pain, and bloody mucus in his stool, symptoms he attributed to diet: "I was young. I just assumed that I was eating the wrong things." He continued to live with these symptoms for five months until they could no longer be contained: "it came to a point where I couldn't leave the house without knowing where the closest bathroom was." Kimberly (26, white, colorectal), experienced similar symptoms that she "didn't know what to do with." As a young professional in a large metropolitan area, she was working to establish herself and "didn't have time to take a breath, let alone deal with these symptoms." Kimberly's experience highlights an additional barrier to timely diagnosis for young adults: how occupational and familial demands can supersede attention to personal health.

Around half of young adults with colorectal cancer described a hesitancy to discuss symptoms deemed "gross" or "disgusting" with healthcare providers. When reflecting on why she delayed help-seeking behavior for so long, Kimberly (26, white, colorectal) highlights the "less glamorous" symptoms of colorectal cancer – blood in the stool, changes in bowel habits, and diarrhea and constipation – particularly when compared to breast or ovarian cancers: "None of it is pretty, and no one wants to talk about it." Heather (31, white, colorectal) recalls a similar hesitancy to discuss her symptoms (bloody stool, bloating, and intestinal pain): "I was super nervous before I got diagnosed to talk to anybody about poop. Nobody likes to do it. Even my doctors, I didn't want to talk to my doctors about [my poop]. So, I sat on my symptoms for about six



months.”

This stigma has two results, it diminishes public awareness of the symptoms of colorectal cancer, making individuals more likely to “contain” symptoms like bloody stool as normal. While it is likely that individuals of all ages experience bodily stigma, stigma is especially salient in young adulthood (Saunders 2014). Further, the social construction of cancer awareness in older adulthood and increases in the health care capital of older adults (resulting from increased engagement in the medical system) may result in action, despite the embarrassment. For young adults, life-disrupting symptoms are contained in relation to their age and assumed health status, and increases the likelihood that young adults will not seek help for symptoms deemed “embarrassing” and “disgusting.”

### **Experience of Professional Diagnosis**

The following section examines the second sub-topic in the diagnosis stories of young adults: interactions with the medical system. In seeking a professional diagnosis, young adults encountered multiple medical professionals in various settings before a diagnosis event occurred. In these accounts, attention was given to the help-seeking process and engagement with the medical system. A central theme in the process of professional diagnosis was the perception that *age* was central to interactions with healthcare providers, clinicians, and medical systems. While the previous section described how, for some young adults, age (and the cultural associations with health) impacted the interpretation of their own bodily sensations, this section explores how young adults’ perceived age to negatively impact how clinicians interpreted symptoms in young adult bodies and structured access to diagnostic testing. These findings illustrate

that some young adults attribute delay in diagnosis to the age-related biases healthcare practitioners hold. These perceptions may impact young adults' confidence in healthcare providers as they progress through diagnosis, treatment, and long-term, follow-up care.

*A note on Individualizing Containment*

While my findings demonstrate that young adults often contain symptoms of cancer that were vague or mild before seeking a professional diagnosis, this containment should not be understood as the primary reason for delays. It is important to note that the tendency to focus on the actions of individual young adults obscures the role of institutional practices and patient-doctor interactions that are often central to the story of delayed diagnosis. It is also true that some young adults who contained their symptoms and delayed help-seeking behaviors experienced a delay in professional diagnosis when they eventually sought care. In such instances, young adults perceived the same lack-of concerns from health care providers and often struggled to attain a concrete diagnosis, despite persistent symptoms. Before continuing with a discussion of the experience of professional diagnosis, I highlight the following excerpt from Jasmine (38, Black, colorectal), who describes her frustration at this tendency to blame the young adult for failing to acknowledge their own symptoms or not seeking medical care:

It is a perplexing thing; people are just so stumped by it. I got sick when I was under 40 with an advanced stage, and people cannot get their head around it.

People are just dumbfounded at the fact. They're like, "*were you not going to the doctor? Were you not taking care of yourself? Do you have insurance?*" That was one of the questions that came up multiple times. "*Well, do you have insurance?*" And I'm like, yeah, of course, I have insurance. And they're like, "well, were you

not going to the doctor?" Of course, I was going to a doctor, but I was being misdiagnosed or underdiagnosed, or whatever you want to call it. I wasn't diagnosed.

Jasmine sought the care of numerous primary care and alternative care doctors over two years of symptoms. Her condition could have been easily diagnosed if her doctors had sought the fundamental cause of her symptoms. Unfortunately, things “weren’t followed up on” and Jasmine was not diagnosed until she sought emergency care for an acute health event.

### *Physician Related Delay*

A common narrative in the diagnosis stories of young adults was the difficulty securing a professional diagnosis, with over half of young adults perceiving a physician-related delay in diagnosis. Perceived delays were most likely to occur when young adults experienced symptoms understood by professionals to be "vague," such as fatigue, fever, changes in bowel movements, and unexplained pain<sup>5</sup>. These symptoms most commonly occurred with blood and colorectal cancers. The process of professional diagnosis was described as a struggle, with an overarching obstacle being patient age and assumption of health. During this phase of the process of diagnosis, respondents had consultations with general practitioners, specialists, and alternative care providers over several months and, in some cases, years.

The dominant perception, expressed almost universally by young adults that experienced a "delay" in professional diagnosis, was that when seeking-help, their

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<sup>5</sup> While these conditions may have been considered “sub-acute” (a relatively recent onset) at some point in the diagnostic process, the term is also used to describe symptoms that persist longer than one month but less than three months. Given that symptoms persisted, without a diagnosis, for as long as two years, this classification is inappropriate.

symptoms were met with a lack of concern by doctors and healthcare providers. This perceived lack of concern included age-based assumptions of health (in young adulthood), cancer risk (in older adults), a lack of social power, and gendered and racial stereotypes. Importantly, these themes are not mutually exclusive and were often co-occurring, overlapping, and intersecting. In the following section, I detail how a "lack of concern" based on patient age is perceived to be the driving cause of delays in professional diagnosis for young adults. I also describe the role of social capital and access to medical networks in mitigating the age-based perceived lack of concern.

Mark (28, white, blood), who experienced a 6-month delay in diagnosis after experiencing weight loss, persistent fevers, and drenching night sweats, characterizes his age as central to his doctor's interpretation of his "textbook" symptoms as a "run of the mill viral infection." Mark recalls that his doctor's response to his symptoms -- months of low-grade fevers and drenching night sweats -- was "you know, you're young, you're healthy, we don't have a lot of concern really." For Mark, this lack of concern was solidified when his doctor failed to call him back with the results of his blood test. After learning more about the illness, Mark expresses frustration with his doctor's failure to recognize the symptoms that he characterizes as "textbook" and perceives his age, and its associations of health, as a *blind spot* in his successful diagnosis: "And the frustrating thing, looking back on it, is how textbook [my symptoms were]. And yes, [my doctor] was not an oncologist, but as someone in the medical profession, you should be able to recognize these textbook illnesses."

For Hector (19, Latinx, blood), the lack of social power in young adulthood was articulated as the reason for a perceived lack of concern in patient-physician interactions.

In explaining why clinicians "did not take [my] concerns seriously," Hector describes how the expectations of health placed on young bodies were exacerbated by his age-based deficit of social power when engaging with doctors. Hector's mother, an immigrant who spoke very little English, lacked the flexibility to take him to the doctor, communicate the severity of his symptoms, or advocate for further diagnostic testing. Instead, Hector scheduled and attended medical appointments alone, where he was assessed by unfamiliar pediatricians that he perceived to be unaccustomed to examining patients without a parent. He asserts: They did not take my concerns seriously, "I don't think they were used to interacting with a young adult without parents." In reflecting on the reason for his delay, he states: "I think it would be a lack of accountability I was perceived to have on my end maybe and a lack of concern on their end." Often, studies of barriers to care emphasize the actions of the individual patient rather than the medical system.

Almost young adults with colorectal cancer perceived that their symptoms were met with a lack of concern by doctors and healthcare providers. Christopher (21, white, colorectal) recalls a medical specialist explicitly referencing his age when seeking a diagnosis for pain, bloody stool, and bloating: "He told me you're too young to have colon cancer and said [my symptoms] were probably a hemorrhoid or an anal fissure." Like other young adults, Christopher perceived a lack of concern from his doctor, "He didn't take me seriously," a perception reinforced by the difficulty attaining, scheduling, and getting results from diagnostic tests. When he finally received a colonoscopy, he was rushed to the ER after the procedure and began treatment the following day.

When reflecting on her diagnosis story, Shannon (36, white, colorectal) describes age, presumed health status, and lack of concern as central to the interpretation of her chronic stomach pain: "The response from the nurses was 'oh, you're so healthy.' Even [the primary care physician] did not seem concerned at all about my symptoms... If she had said, I think you should go see a gastroenterologist or that I should have a colonoscopy, we definitely would have caught it sooner." Six months later, Shannon was diagnosed with metastatic disease. While she is careful not to make assumptions about what an earlier diagnosis would have meant for her prognosis, she does perceive her age to be central to her experience of delay:

I can't really say in retrospect whether those six months would have made a difference in my diagnosis. I could have been diagnosed with the same stage at that point. It could have already spread far enough to metastasize. It's hard to say for sure, but I definitely think that that delay in the diagnosis had a lot to do with my age.

While Shannon is unsure how an earlier diagnosis would impact her illness trajectory and cancer staging, it is important to note that colorectal cancer is considered curable if caught in the early stages.

Heather (31, white, colorectal) recalls how the intersection of gender, age, and illness impacted how she perceived her doctor to interpret her cancer symptoms when seeking help for bloody stool, abdominal pain and bloating.

He was just sure that I was too stressed. I mean, he even went so far as to tell me that I need to learn to calm down and meditate... He also gave me a really high-

powered Zantac, and I didn't know at the time that it was Zantac. He said I've got something to help with the bleeding. You need to take this every day.

Heather's doctor's assumption that she was "*too stressed*" and that she "*need[ed] to calm down*" echo the minimization of women's health concerns by medical professionals and female hysteria (Tasca et al. 2012). Female hysteria was understood as a white women's disease, reflecting the differing relationships of Black Indigenous People of Color (BIPOC) women to pain and the body (Brigs 2000). Significantly, in the case of some young adults, this devaluation of women's voices interacts with assumptions of young adulthood, contributing to increased misdiagnosis by health care professionals. Because of this devaluation and disrespect, Heather "went about her business" and failed to follow up with her doctor, despite her symptoms becoming more persistent. When reflecting on how age impacted her delay in diagnosis, Heather recalls her doctor's disbelief in her cancer diagnosis: "when we took the results back to [my doctor], he was like, 'you're too young for this cancer, and you're a woman so you shouldn't have this cancer.'" Here, age and gender construct colorectal cancer as a disease of old men, shaping conceptions of risk access to diagnostic testing.

Jasmine (38, Black, colorectal) describes being misdiagnosed for two years, during which she experienced stomach pain, digestive problems, chronic anemia, and rapid weight loss; symptoms that she describes as a "*tell* for anybody that something's wrong." During this period, she saw multiple doctors, including those focusing on primary care, gastroenterology, and holistic medicine: "My doctors assumed I was healthy as a horse. So they were like iron supplements, iron supplements, iron supplements, eat more meat, eat more spinach, you know, a protein-based diet. They

thought that I just wasn't getting enough nutrients." Emphasizing lifestyle choices, Jasmine's doctors failed to identify the fundamental cause of her anemia and applauded her weight loss when she lost 60 pounds in two and a half months. Based on her presentation of symptoms and the current screening guides, Jasmine should have received a colonoscopy.

The only young adult with colorectal cancer that did not perceive a lack of concern among clinicians was Alexis (38, white, colorectal), whose undiagnosed disease progressed to an acute stage. She was living abroad in a country with universal healthcare when she experienced a ten-minute seizure. She was taken to the hospital, where they performed an MRI, which found swelling in the brain, "they didn't know if it was an infection or a tumor that was causing the swelling." Learning of her family history of colorectal cancer, they performed a colonoscopy. After returning to the U.S., it was confirmed that the primary source of cancer was the colon and the secondary source was the brain.

#### *Access to Colorectal Screenings*

Almost all young adults with colorectal cancer articulated an additional age-related blind spot in their experience with the medical system: the difficulty of attaining a colonoscopy. This difficulty was attributed to age and the construction of colorectal cancer as a disease impacting "old men." This cultural construction of colorectal cancer as a disease of old age has been institutionalized into existing colorectal cancer screening guidelines, which suggest that screening begins at the age of 45. At the same time, current guidelines state that screening should start at the age of 45 unless there is either a family history or a patient has experienced "persistent" gastrointestinal issues. Despite



these guidelines, young adults with a family history and persistent symptoms could not attain diagnostic testing. The difficulty accessing a colonoscopy is particularly alarming as rates of colon and rectal cancer in young adults, specifically, those under 35, are projected to increase by 90% and 125% by 2030 (Underferth 2020).

In reflecting on her struggle for diagnostic screening, Amira (30, white, colorectal) describes having to "beg" her doctor to prescribe the colonoscopy that would provide her with a diagnosis despite experiencing almost three years of symptoms: "I knew something was wrong. I knew that something was being missed." Highlighting the age-based blindspot in cancer screenings, she labels her experience as "age-discrimination," stating, "because I was under this magic age of 45 and there was no family history, they did not think to do a colonoscopy." Amira's experience demonstrates how age becomes formalized by medical institutions, shaping access to medical screenings and diagnostic technology. Even when young adults present with symptoms that should trigger diagnostic screenings, age, as a "magic number," shapes access.

While current protocol states that those under 45 with a family history of colorectal cancer should undergo screening, family history did not guarantee access to a colonoscopy. Carlos (32, Latinx, colorectal), who experienced severe abdominal pain, bloody stool, and constipation, describes his difficulty attaining any diagnostic testing, despite a family history of early-onset colorectal cancer. Carlos' experience illustrates how age-specific constructions of risk are used as justifications as to why further diagnostic testing was unnecessary:

No one took me seriously. Even when I brought up my family history of colon cancer, that my grandmother had it in her thirties, and I was nearing my thirties at

the time. I kept hearing, “you're too young. I'm too young for that. That's an old man's disease.”

Despite not having health insurance, Carlos returned to the emergency room on multiple occasions as his symptoms increased in severity. Hospital personnel coded this help-seeking as drug-seeking despite his family history and explicit requests for diagnostic testing: “I told them again I had a family history of colorectal cancer, and that I just wanted a CT scan, and that I was not looking for pain management. They basically treated me like a junkie and escorted me out.” A few weeks later, this happened again: “I was asked about opioids, and asked why I wanted the drug, and, if I needed rehab assistance or whatever.” Carlos characterizes his various points of contact with the medical system as “absolutely no help” and asserts, “no one was going to help me diagnose what was going on.” Carlos, who repeatedly sought care despite being uninsured, was familiar with the often-unrecognized symptoms of colorectal cancer and was aware of his increased risk of early-onset disease, which contradicts previous research that emphasizes insurance status and patient knowledge as a central barrier to care. Occurring within the height of the opioid epidemic, Carlos perceives that his age and the expectation that old bodies have cancer and young bodies abuse drugs as the reason for his doctors’ lack of concern, the failure to recognize the severity of his symptoms, and his delayed diagnosis. Amira's and Carlos' experiences demonstrate how the formal use of age in patient risk assessments can overshadow factors like symptom presentation and family history. While such screenings may improve early and pre-disease detection, they also shape conceptions of risk.

### *Perceptions of Racism*

While many young adults referenced age as central to their misdiagnosis experiences, BIPOC respondents perceived racial identity and experiences of racism, in addition to age, as central to patient-professional interactions. These experiences were more likely when BIPOC respondents sought a diagnosis in hospitals in majority-white communities and engaged with majority-white healthcare professionals, or what Anderson (2015) refers to as "white spaces." While white spaces vary, their most distinct and visible feature is their "overwhelming presence of white people" (Anderson 2015:13). In such spaces, stereotypes or assumptions about members of a racial group "rule perceptions" (Anderson 2015). The medical field remains a white-dominated profession with high rates of occupational segregation by race.

Around half of BIPOC young adults perceived that racial stereotypes negatively influenced their diagnosis experiences. For example, when recalling her delay in professional diagnosis, Nicole (28, blood, Asian Indian) describes how the stereotype of the perpetual foreigner made her doctor think she was suffering from "exotic illnesses" uncommon to the United States:

My parents are from India, but I was born in the U.S. When talking to my [white] doctor, he was sure I had tuberculosis because I was Indian and had therefore been exposed to Tuberculosis. He kept talking about a recent paper he had read. I told him I had not left the country recently and had a TB vaccine when I [recently] started a new job, but he didn't listen.

While rare in the United States, tuberculosis remains one of the top causes of death worldwide. India has the highest disease incidence, accounting for more than a quarter of

all cases (WHO). Nicole perceives that racialized stereotype of the perpetual foreignness of Asian Americans contributed to her doctor's (incorrect) interpretation of her symptoms and thus her delay in diagnosis. The Asian American as a “forever foreigner” or “racialized foreigner” implies that cultural and physical differences render Asians inassimilable to the white normality, making Asians always seen as an immigrant or “foreigner-within” regardless of citizenship status (Tuan 1998; Fujiwara 2008). As a racialized foreigner, Nicole perceived that her doctor assumed that her cancer symptoms resulted from travel to a part of the world with high rates of Tuberculosis transmission, India, even though her case expressly contradicted this assumption. Here, the stereotype of the forever foreigner intersects with cultural assumptions of health to shape interactions with health care professionals.

Eric (34, Black, blood) also perceives that racialized stereotypes influenced interactions with healthcare professionals resulting in the misdiagnosis of cancer relapse or when cancer returns after not being detected. After Eric’s initial treatment was successful, he was prescribed maintenance chemotherapy, taken orally multiple times a day, to prevent a recurrence. During this period, his oncologist closely monitored him with regular blood tests to detect evidence of cancer's return. Over several months, Eric’s lab work began to show irregularities. Rather than follow up with more testing, Eric’s doctor assumed he was not taking his medicine as prescribed. When recalling this misdiagnosis of a recurrence, Eric emphasizes the role of his race in impacting his doctor's interpretation of his symptoms:

It happened on more than one occasion. He'd start yelling at me and say, "you're not taking your medicine. If you were, your labs wouldn't say this and that," and I

was like, "I am taking them like I should have." Just constant accusations all the time. And, looking back at it now, when he was accusing me of these things and the labs that were showing up, that was the start of my relapse... Those labs changing and him throwing those accusations at me, it was a start of the whole actual relapse. It seemed like he thought I was dumb or uneducated. I guess he just assumed I was just another Black face in his office, lying to him about who knows what or why. It was never anything overt, but I mean, I've been doing this whole thing of being a Black man in America for a while now, and I can sort of pick up on the underlying tones of what's being said, and I definitely felt in that situation that's what was going on with him.

Prior research identifies a variety of racialized and gendered stereotypes that Black men encounter, including that they are irresponsible, lazy, untruthful, and uneducated, which in turn influences the treatment of Black men (Taylor et al. 2019). In this context, Eric felt racial stereotypes negatively impacted his doctor's perception of him and how his lab results were interpreted – assuming the irregularities resulted from noncompliance rather than signs of a recurrence. Physicians believe Black people are less likely to comply with treatment making them less likely to put effort into diagnosing a patient's problem (van Ryn and Burke 2000). Eric's example highlights the material embodied consequences of racism in interactions with doctors and medical practitioners. As Eric had previously been diagnosed with blood cancer and taking maintenance chemotherapy, his doctor should have been on high alert to any potential abnormalities in his labs. As such, the assumption that he was healthy because of his age was already disrupted. Rather than

follow up accordingly when his labs demonstrated abnormalities, he was met with accusations of noncompliance that postponed the diagnosis of his recurrence.

The location of care received was an important contributing factor in the perception that racism negatively impacted diagnosis experience. Those young adults that received care at rural clinics or those in majority-white areas were more likely to express experiences of racism in interpersonal interactions. On the other hand, BIPOC respondents who received care in more racially-diverse areas directly cited this diversity as protective against experiences of overt racism. For example, for Martin (28, multiracial, blood), "living in" an area that is "really racially diverse" meant that he was spared experiences of over-racism when seeking a professional diagnosis. For him, age, rather than race, was more salient and the reason for his misdiagnosis. Likewise, Carlos (32, Latinx, colorectal) described living in a metropolitan area and "not looking" Latino as protective against experiences of racism. This highlights the importance of phenotype as Latino men with light skin are less strongly racialized than those with dark skin (Vasquez 2010). In a final example, Jade (29, Black, blood) describes how, after experiencing macroaggressions in a majority-white rural hospital in the South East, she relocated to a large metropolitan area to receive care in an area with more racial diversity: "When taking my medical history, they would ask me questions like, 'do you know your parents?'" In reflection, she emphasized the importance of "having doctors and nurses who look like me."

#### *Health Care Social Capital*

For young adults with class privilege, social networks played an important role in mitigating the age-related blind spots in professional diagnosis. This does not mean that

those young adults with access to healthcare professionals in their social networks did not experience any delays in symptom interpretation. Rather, young adults with access to social networks that contained healthcare professionals had access to informal consultations that impacted when they sought help, could more quickly navigate diagnostic testing, and were provided informal referrals to high-quality doctors. These young adults have “health care cultural capital” or “the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviors, and interactional styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal health care relationships” (Shim 2010:1). I extend this concept to focus not only on cultural capital but rather emphasize the social capital and thus social networks of young adults. While health care capital did not always override the negative value associated with age, it did provide access to medical and healthcare professionals who were perceived to have concern for the young adult patient. As such, the extra concern and time provided to the professional symptom interpretation were often satisfactory to result in a diagnosis. Such capital paired with social awareness of certain cancer campaigns to shape diagnosis experiences.

Amanda’s (33, white, breast) social network contained healthcare professionals and access to specialized medical knowledge that disrupted her initial interpretation of herself as “healthy” and her bodily changes as “normal.” When Amanda first experienced changes in breast tissue, she attributed them to normal physiological changes during pregnancy. Working at a birth center, she sought the input of a friend and coworker, an experienced midwife, to verify this interpretation. After an informal examination, this midwife felt her symptoms were inconsistent with normal breast changes during

pregnancy and quickly referred Amanda to an "overly educated" local physician. Exercising the midwife's social network, Amanda was seen quickly: "I got in the next day, and she took some measurements and ended up calling a surgical oncologist that same day." In this instance, Amanda's social network provided access to a healthcare professional that impacted the interpretation of her bodily sensation as a symptom and a personal referral to a trusted doctor.

In another example, Lindsay (37 white, gynecological) employed her health care capital to gain access to a highly qualified medical specialist after she perceived a lack of concern from her "regular" doctor during her initial help-seeking:

I went to a gynecologist, like a regular [gynecologist] at a regular facility. I didn't like how he was treating me and all that...so luckily, I have a really close family friend, and her father is head of another department at [a large cancer treatment and research institution]. We legitimately went to [the cancer center] because this oncologist took me on as just like a favor to a friend.

After the "regular gynecologist" minimized and misdiagnosed Lindsay's symptoms, she mobilized her social network to quickly receive a second opinion and, ultimately, a cancer diagnosis. Unlike other young adults, Lindsay received care from a prestigious oncologist at a world-renowned cancer center *prior* to her cancer diagnosis. This means that she did not have to navigate the complicated referral process and benefited from continuity of care.

Like Lindsay, Monica (28, white, thyroid), who was also dissatisfied with her initial care, describes how her social network provided access to a specialized endocrinologist who had experience in treating cancer patients:



My mother actually is friends with one of the top endocrinologists in America. So [my mother has] been backing up everything that my doctors have said with him. I can't go to [this doctor] because he's [in a different state]. Whenever I was having all this stress [with my doctor]...she asked her friend for a recommendation, and he taught this young lady that I started going to. And so it's the second best thing to going to him.

Access to a more prestigious endocrinologist had significant implications for Monica's treatment protocol and outcome. She later learned that she was undertreated by her first doctor, who considered her small nodule low-risk, despite it "going through a blood vessel." Thyroid cancer mainly metastasizes through the blood, and invasion to a blood vessel necessitates more aggressive treatment, including radioactive iodine treatment and further diagnostic testing, "my second doctor [said] that the blood vessel definitely is a high risk... and I definitely should have had the radioactive iodine [treatment] because if there was anything left anywhere else in my body, then my first doctor didn't catch it." Monica's experience highlights a critical extension of the concept of health care capital as it *was mobilized through a parent*, this again emphasizes the role of the family in addressing the institutional limitations of young adults with cancer.

## **Discussion**

In the following section, I discuss all three research questions addressed in this chapter. First, what is the diagnosis experience for an off-time cancer diagnosis? Then, what is the embodied experience of self-diagnosis for young adults? Finally, what is the experience of a professional diagnosis for young adults?

Young adults experience diagnosis as a longitudinal, multi-sited process rather than a single realization event. The accounts of diagnosis were organized into two stages: self-diagnosis and professional diagnosis. Young adult accounts of diagnosis began when they *retrospectively* identified the start of cancer symptoms. They described when and how unexplained bodily sensations (that would be retrospectively defined as symptoms of cancer) were interpreted, explained, and acted upon. They then described the stage of professional diagnosis, emphasizing patient-provider interactions and all engagement with the medical system that came before the diagnosis event. The specific realization event was given little attention, serving as the conclusion to the diagnosis story rather than the central focus of the diagnosis experience.

These findings are consistent with prior research that shows patients have broader interpretations of diagnosis beyond a single day or event. A review of patients' written accounts of diagnosis shows that stories typically began with first symptoms and included multiple clinic interactions (Salander 2002). It also supports findings by Leydon et al. (2003) that show interactions up to the point of diagnosis influenced patient expectations about future care. Difficulty attaining a diagnosis undermined faith in the medical system in general and the ability of non-specialists (non-oncologists) to provide competent care. These findings are also consistent with previous research that finds that patient experience with the medical system prior to diagnosis-event impacts how the diagnosis is internalized (Schaepe 2011).

The chapter then interrogates the embodied experience of self-diagnosis. The experience of self-diagnosis is impacted by the physical manifestation of cancer in a young adult's body. Young adults that identified a lump/swelling as part of the self-

diagnosis process were likely to identify this bodily sensation as abnormal and seek a professional medical consultation. Those young adults that experienced lesser-recognized cancer symptoms were likely to contain symptoms with explanations based on biography and lifestyle choices, specifically age-based assumptions of health and engagement in health-related activities. In some cases, cancer symptoms were not only contained by lifestyle choices but also explained by them. In the case of colorectal cancer, the social stigma of some regions of the body made young adults feel embarrassed or uncomfortable discussing their symptoms with their doctor until they were so severe and could no longer be contained.

Young adults' experience with self-diagnosis aligns with previous research in symptom interpretation (Anderson 2010; Anderson et al. 2015). Prior research stresses that the successful interpretation of an unexplained bodily sensation as a symptom of illness is embedded in social and cultural context (Hays 2008). The quick interpretation of lumps/swelling as abnormal reflects the cultural recognition of an unexplained lump/swelling as the most recognized cancer symptom. Previous research also describes how potential symptoms may be contained based on personal biography, perceptions of risk, and lifestyle choice (Anderson et al. 2010). Assumptions about the life course shape understandings of the self (Kohli and Meyer 1986; Gubrium et al. 1994). My findings demonstrating how assumptions of health in young adulthood function to shape the interpretation of bodily sensations. Prior scholarship also details the emotional labor and negation associated with contested illnesses (Brown, Morello-Frosch, and Zavestoski 2012). My findings differ as the illnesses in question are not contested. For example, in

the case of colorectal cancer, the most commonly “missed” diagnosis in the experiences of my respondents, is easily diagnosed with a colonoscopy.

My findings complicate previous research that asserts concern about wasting a clinician’s time, denial, and fear as reasons for patient-based delays (Smith and Anderson 1985). My findings suggest that for young adults, patient delays are most often attributed to socially constructed awareness of certain types of cancer and certain types of cancer symptoms. I also find that the circulation of information about commonly experienced cancer symptoms works against age-related blind spots. Widely- recognized potential cancer symptoms are recognized to require immediate consultation, regardless of age-related assumptions of health. As such, blind spots matter most with cancer symptoms considered "vague" either because they are mild or because they do not have social awareness campaigns and information circulating about them. In this way, the circulation of information works against the age-related assumptions of health that permeate cultural understandings. For young adults with lesser-known cancer symptoms, age and assumptions of health are central to the interpretation and containment of their unexplained bodily sensations.

These findings have important implications. First, they demonstrate that the cultural association of cancer with unexplained lumps has extended beyond breast cancer to include incidents of cancer that may include unexplained lumps/swelling, like testicular cancer and some cases of lymphomas. They also show how drives to increase awareness of other lesser-recognized cancer symptoms must recognize the importance of challenging other age-specific constrictions of young adulthood as a period of health. This means that increased awareness of certain common cancer symptoms, like blood in the

stool, may contribute to more expedited symptom recognition among young adults.

This chapter also explored a second research question, what is the embodied experience of professional diagnosis? For many young adults, attaining a professional diagnosis was difficult, with the majority of young adults experiencing a delayed or misdiagnosis. Misdiagnosis was more likely to occur when young adults did not experience the most commonly recognized cancer symptoms: a lump or swelling. The dominant perception, expressed almost universally by young adults that experienced a delay in professional diagnosis, was that when seeking-help, their symptoms were met with a lack of concern by doctors and healthcare providers. This perceived lack of concern included age-based assumptions of health (in young adulthood), cancer risk (in older adults), a lack of social power, and gendered and racial stereotypes. Around half of BIPOC respondents perceived racial identity and experiences of racism, in addition to age, as central to patient-professional interactions. For those that did not perceive racism to impact experiences, receiving treatment in diverse areas with racially diverse clinicians was articulated as protective against experiences of racism.

For young adults with race and class privilege, social networks played an important role in mitigating the age-related blind spots in professional diagnosis, providing access to informal consultations, expediting medical delays, and providing informal referrals to high-quality doctors. This builds on literature documenting the importance of social networks in facilitating help-seeking (Burgess et al. 2006; Burgess et al. 1998; Macleod et al. 2009; Smith, Pope, and Botha 2005). I extend this line of inquiry, showing how social networks mediate age-related blind spots. I show how networks not only encourage young adults to seek care for abnormal bodily sensations,

but also to continue seeking care after concerns have been diminished. Further, networks allowed some access to second opinions that would be more sympathetic to concerns. In this dissertation, I am extending the insight provided by the cultural health capital framework by underscoring age as a crucial component to who is more or less likely to have "cultural health capital" (Shim 2010). I also extend the concept by emphasizing social networks and access to informal medical consultation.

My findings offer insight into persistent racialized health outcomes for young adults with cancer. Black and Latinx young adults experience increased mortality across all cancers (Williams et al. 2012). While biomedicine often reduces racial disparities to differences in financial resources (Lee 2008), this racial disparity remains when controlling for insurance status and stage of presentation (Chao et al. 2015). One potential explanation for racialized health outcomes is racialized differences in diagnosis and treatment (see: Colton 2016). Others have demonstrated the perceived role of racism in encounters with medical professionals. These studies have demonstrated how BIPOC patients' concerns are taken less seriously than the concerns of white patients and that physicians believe Black people are less likely to comply with treatment (van Ryn and Burke 2000), making them less likely to put effort into diagnosing a patient's problem. My findings support these explanations, documenting perceptions of racism in patient-provider interactions for BIPOC young adults. These findings also extend this body of research, demonstrating how the racial demographics of the community and hospital impact patient-provider interactions. According to the Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care (2003:172-3):

Negative stereotypes about minorities' health explicitly or implicitly by physicians, can contribute to health disparities in a number of ways...conditions of time pressure, high cognitive demand, and stress are common to many healthcare settings, making these settings "ripe" for the activation of stereotypes.

Literature on racial health disparities often frames experiences of racism as "personal and situational," focusing on "unintentional" racism on the parts of health care providers.

Rather than understanding healthcare providers as "individuals" and encounters of racism as "situational," I understand healthcare providers as the embodiment of the medical system. Young adults' relationships with the medical system occur through various interactions. The choices the medical system makes in terms of training, support, and risk assessment for doctors, clinicians, and administrative staff communicate important messages about the medical system's relationship to bodies seeking care (See: Ernst, Nguyen, and Taylor 2013)<sup>6</sup>.

These findings have important implications. First, these perceptions may impact young adults' confidence in healthcare providers as they progress through diagnosis, treatment, and long-term follow-up care (see: Leydon et al. 2003; Schaepe 2011). They speak to the need for more racial and ethnic diversity within medicine overall and within medical specialties.

Overall, my findings demonstrate how the sociocultural construction of young adulthood as a life stage of health and assumptions of cancer as a disease of old-age are central to the diagnosis process for young adults with cancer. As such, sociocultural

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<sup>6</sup> In their audit study of "welfare offices" in Washington state, Ernst, Nguyen, and Taylor (2013: 1284), examine institutional racism by examining citizen-state interactions, asking, "Does the state send different messages about citizenship to individuals according to race?" While methodological differences persist, the view of individuals as larger state actors supports the idea that engagements with the medical system occur not only on an individual level.

expectations of health dictate an individual's perception of their own bodily sensations – and if they are contained – and how an individual perceives their bodily sensations to be interpreted by health care providers. This yields insight into how life course stage shapes young adult understanding of their bodies and how their bodies are perceived by health care professionals. I offer the term 'age-related blind spots," where young adults, clinicians, and medical systems are slow to recognize ill health in some young adult bodies, as a conceptual tool to capture how life course stage impacts diagnosis. My findings show that the simultaneous assumptions of health in young adulthood and cultural construction of cancer as a disease of old-age impact perception of cancer risk and symptom interpretation by individuals and health care providers and shape institutional policies and practices, leading to age-related blind spots for individuals, and bodies, that fall outside of societal expectations.



## CHAPTER III

### “THE YOUNGEST IN THE ROOM” EMBODIED ABERRATION IN TREATMENT

It is a rainy Tuesday morning. We pull into the already crowded parking lot at our local cancer center. The walls of the elevator are plastered with “Hope” and “Cure” in hues of light yellow, blue, and green. As we move through the cancer center, eyes follow us; we are met with looks of concern and pity.

We take a seat in the waiting room. The chairs are wooden with blue cushions. We opt for a double chair. The light wooden side tables have orchids on them. The orchids are always in bloom, a picture of health and beauty. During my time in this waiting room, I will witness a flower service rotating the plants, ensuring that patients are met with blossoms at the height of health.

His name is called. We follow an infusion nurse to the chemotherapy room. The flooring changes from carpet to tile. The chemo room is large and sterile, with small stations separated by a curtain for privacy. Each patient has their own small TV, a reclining chair, and a ready IV bag. We can pick the chair of our choice. My partner, who opted against a pic, or central line to the heart, spends his first few moments getting an IV. Early on, he was told he had “good veins,” but over time, the blood work and subsequent doses of chemotherapy have taken their toll, and their quality has diminished. It takes a few times to get it right. A few weeks before, a bad seal caused some of the drugs to spill into his skin, leaving a still-visible discoloration. .... He needs to pee. I get up with him, helping him roll his IV bag into the centrally located bathroom. I know that his urine will be bright red from doxorubicin, a chemo drug known as the “Red Devil.” I feel all the eyes in the room on us. As I close the bathroom door and walk back to our seat, an older white woman whispers to me, “*what kind of cancer does he have? He’s so young...*”.

I wrote the preceding passage while my partner received treatment for Hodgkin's Lymphoma in late May 2016. Throughout my partner's cancer treatment, I took, for lack of a better word, field notes, documenting my experience as a caregiver. These field notes do not serve as data for this project. I have no plans for them to become more than they are; they are his story, not mine. However, I offer a portion of them here as a vignette to

illuminate how mundane experiences in a cancer center – moving through space – communicate who is expected and unexpected in an environment.

A body's experience of illness is unique and personal while also inextricable from the social realm in which it is embedded. While the body's experiences of cancer treatment and side effects may feel deeply individual, the significance attached to such experiences cannot be detached from the cultural expectations placed on that body; what it *should* and *should not* experience (Corbin 2003). As asserted by Douglas (2003:65), "the social body constrains the way the physical body is perceived," and the body's physical experience is "modified by the social categories through which it is known." This means that societal expectations and assumptions of young adult bodies shape the physical experience of a young adult body.

The cultural expectations placed on bodies become reflected in and codified by institutional arrangements. Spaces are designed for certain bodies. Bodies that occupy spaces not designed to accommodate them become othered, and bodies that challenge social expectations can be objectified, feel uncomfortable, and "out of place" (Ahmed 2007; Chandler 2019). For example, BIPOC (Black Indigenous, People of Color) bodies in white spaces (Fanon 2008; Anderson 2015; Woody 2021) and women in male-dominated occupations (Cassell 1997). Ahmed (2007) demonstrates how whiteness orients bodies, impacting what they "do" and how they "take up space." In white spaces, inhabiting a body that is not white renders whiteness visible (Ahmed 2007; Woody 2021).

The role of the institutional environment in shaping the young adult experience of aberration can be further explained with the concept of misfit. Disability scholar

Rosemary Garland Thompson conceptualizes the relationship between the material environment and the body as misfit (2011). From this perspective, out-of-placeness can be understood as *misfit* that arises from an environment that does not sustain the shape and function of the body that enters it. With this, emphasis is placed on the material context of a space; environments are built for and sustain the "majority bodies," producing *fit*. The case of young adults with cancer provides a unique extension of this theorizing as fit and misfit is based not on the body of the individual but rather on the relational engagement of a body within the context of an institutional environment. Treatment centers are designed for the "majority bodies" of older patients. In this chapter, I conceptualize "cancer treatment" as an *institutionalized space* in-which young adults experience aberration in the physical space and medical practice. I describe how the consequence of this aberration, or misfit, contributes to a loss of agency for young adult bodies. I conclude with an in-depth discussion of one particularly salient consequence of aberration: loss of reproductive autonomy. My findings also suggest variations exist in the experience and consequences of aberration based on race, class, and gender.

### **Young adult Bodies as Aberration**

The first theme expressed by the vast majority of young adult cancer patients was *bodily aberration*. I define bodily aberration as the experience that young adult bodies are outside the norm and feel "out of place." Fit occurs when one is "suited to the circumstances and conditions of the environment, of satisfying its requirements in a way so as not to stand out, make a scene, or disrupt through countering expectations" (Garland-Thompson 2011). Aberration represents both the embodied experience of the

young adult patient and the positionality of a young adult patient in medical knowledge. This aberration results in a loss of agency for young adults.

### *Aberration in the Physical Space*

Engaging with the cancer center was associated with embodied aberration. Here, aberration refers to the sense that young adult bodies with cancer were abnormal or out-of-place in those spaces dedicated to the treatment of cancer. Young adult bodies stood out in these spaces, challenging expectations of who is a cancer patient and what a cancer patient looks like. Out-of-placeness was communicated by the medical staff, other patients, and the design of the spaces themselves.

The surprised reactions from healthcare personnel communicated aberration. In one case, Paul (33, white, blood) recalls how nurses and administrative staff would assume one of his parents was the patient when they accompanied him to treatment: "I would have to tell them, 'nope, It's me.'" Lindsay (37, white, gynecological) describes the shock exhibited by a research fellow as she sought consent for the donation of Lindsay's organs, "She comes in, and my mom and I are sitting there, we're all giddy and happy and all of this because you know, why wouldn't I be happy I'm just giving away organs...She literally first walks in, and she just like stops in her tracks because she is not expecting somebody of age."

Aberration was also communicated by medical personnel who would question young adults about their symptom presentation, the experience of diagnosis, and family history in ways that communicated the novelty of young adult bodies at treatment centers. For example, Shannon (36, white, colorectal) recalls how her nurses, who were often similar in age, would ask about her symptoms and the diagnosis process in ways that

situated themselves in her experience. In doing so, they communicated the aberration of her body as if they had never before been faced with a young adult patient or considered that young adult bodies could have cancer. She explains, "[the nurses] are in this profession, but they're looking at me like *I need you to tell me how you knew you had cancer*. They're seeing me and thinking, 'Oh my gosh, this is something that could happen to me.'" Shannon also describes similar experiences with other medical doctors (excluding her oncologist) who questioned her about her symptoms. "When you get that from a doctor, it seems weird because, you know, they're a doctor, even if they're not the doctor for colon cancer, it just seems weird that they're asking for that information from the patient."

Young adults describe experiencing "hypervisibility" while receiving treatment and being the subject of stares. Sydney (28, white, blood) recalls receiving "pity stares" while receiving chemotherapy, referring to them as "the worst part of treatment." Jeremy (36, white, blood) recalls experiencing hypervisibility in the cancer center when marked as a cancer patient rather than a visitor accompanying someone else, "I saw few, if anyone, my age. On the occasions that I did [see people my age], they weren't patients... I felt stares and would be asked, you know, 'what kind of cancer do you have.' I remember during chemo, older folks would look at me like, *oh, that's so sad*." Jeremy's experience illuminates how aberration is tied directly to being a young adult cancer patient rather than a young body in a cancer center. He describes being "marked" as a patient in specific locations: while waiting for labs and while receiving chemotherapy, and by the side effects of chemotherapy, "chemo changes your body so much that it triggers... you as a patient." Garland-Thomson describes staring as "social choreography

that marks bodies by enacting a dynamic visual exchange between a spectator and a spectacle” (Sandahl and Auslander 2005:31). Staring communicates that a body is unanticipated and inexplicable. It communicates who is different and who is most unexpected.

Going to the cancer center and being the only young person...I felt like I stood out like a sore thumb in the waiting room and the infusion center [when] compared to everybody else who was there. When you're the only one, it's just like a constant visual reminder that *you're not supposed to be going through this*.

In a different example, Hector (19, Latinx, blood), treated at a pediatric cancer center, also experienced bodily aberration as a young adult. Pediatric cancer centers as "childish" with infantile-themed rooms and too-small furniture. Hector recalls having Marvel and Disney murals painted on the room's walls. Despite aberration in the physical space, pediatric cancer centers did offer patients a level of support unavailable in adult-cancer centers. For example, Hector's mother could stay in an on-site apartment, free of charge, for a few months during his hospitalization, and he and his family received gifts for the Christmas holiday. While welcome, these same services also posed a challenge to the autonomy of young adults, contributing to the "out-of-placeness" of young adult bodies.

#### *Aberration in Medical Practices*

The second articulation of young adult aberration was in medical practices. Medical practices refer to policies and procedures, including treatment protocols, long-term follow-up care, and data on long-term side effects and survival rates.

Young adults were met with a dearth of medical research on young adult bodies. As such, aberrance was articulated in relation to the uncertainty of long-term side effects, late effects, and survival rates for young adults. The invisibility of young adults in cancer research is due in part to demographic patterns and incident rates and treatment advancements. Modern medicine is based on what Foucault (2012 [1977]) refers to as “normalizing judgments,” where the attributes of one are compared to those of others. As young adults are less likely to be diagnosed with cancer, there is less medical information available about the population. Therapies used to treat cancer are associated with the risk of a second cancer later in life, with subsequent malignancies constituting 15 to 20% of all cancer diagnoses (Demoor-Goldschmidt and de Vathaire 2018). This uncertainty yields an age-specific concern for young adults based on their longer life expectancy and higher sensitivity to treatments (Demoor-Goldschmidt and de Vathaire 2018). For example, those receiving radiation therapy to the chest have a greater risk of breast and lung cancer, and some chemotherapy drugs are linked with developing secondary blood cancer. When treated, the patient's age impacts the risk of a second cancer; those treated at a younger age are more likely to develop a secondary cancer.

Young adult participants expressed frustration about the uncertainty of survival rates after the 20 year mark and the risk of a secondary cancer. Wendy (24, white, blood) asserts, "all the research on long-term survival and recurrence rates for young adults with blood cancer are 20-year studies. I was diagnosed at 21. So you know, in 20 years, I'll only be 41. It's like, 'okay, what happens *after* that?'" She continues by clarifying that she is aware of changes in cancer treatments, but still expresses the desire for more information about young adult patients. "Treatments have changed, I get it, but I still

want to know more about [patients] diagnosed under 40.” For Wendy, aberration results from current survival rates assume a patient is diagnosed in later adulthood. Wendy characterizes herself as a medical "guinea pig," a status that violates the expectations of health in young adulthood grounded in culture and the life course, exacerbating unease in her health status.

The out-of-placeness of young bodies in research meant that young adults experienced high levels of uncertainty associated with their current and future health status. Kimberly (26, white, colorectal), whose treatment included the removal of portions of the colon, bladder, and reproductive organs, and the lymphnodes in the pelvis, describes herself as a member of an “invisible cohort.” “My doctors don’t know what to expect from my body because young people don’t usually get this treatment.” This sentiment was also expressed by those with “good” cancers, those that were operable and could be removed completely with surgery. For example, when reflecting on the long-term side effects of her radical hysterectomy, Lindsay (37, white, gynecological) states:

I'm missing organs that produce hormones. So my body does not function. They were removed from my body when I was 34 years old. Instead of being 60, I'll have 30 years without [hormones] in my body. Like what's going to happen... It's so new. It's so recent for women, my age or younger to have, we don't have research on what happened at this age. We're like basically some form of fucked up guinea pigs of like what's going to happen to us.

Numerous young adults echoed this sentiment during a presentation on the importance of long-term follow-up care for young adults with hematological cancers. In one instance, a white man in his late thirties who experienced a secondary blood cancer following



chemotherapy, stood up and asked a prominent hematologist, "why do all the side effects of cancer treatments have to be other cancers? Lung, Colon, Blood. I'm serious, why can't they just make me taller or something?" In our interview, Sydney (28, white, blood) expressed a similar frustration, "I am only 28, and I'd like to live for another 40 or 50 years. I want to know what my long-term risks are." Mark (28, white, blood) describes the frustration of being treated in a space plastered with the language of "hope" but having medical professionals "that are supposed to have the answers" that can only offer unknowns about late effects and are unprepared for long-term follow-up care.

Cancer treatments are standardized into treatment protocols that provide a check the box approach to treatment. Steps must be completed in sequence before advancing to the next step. These guidelines are disseminated by entities like the National Cancer Institute (2022) to "standardize guidelines...in a uniform, clear, and consistent manner." Treatment protocols reflect and reinforce the supremacy of evidence-based medicine and the rhetoric of patient-centered care (Balxter 2009). Evidence based medicine has been critiqued by social science for its erasure of the patient and the discretionary power of the individual clinician (Mykhalovski and Weir 2004). Above all, evidence based medicine, "does not take sufficient account of patient values, nor has it a concept of alternative patient choices that might influence treatment decisions" (Mykhalovski and Weir 2004: 1062).

The erasure of the patient by evidence-based treatment protocols is particularly evident in the experience of young adults with cancer. Young adults are subject to the same treatment protocols as older adults. This means that concerns of central importance to young adults, including reproductive and sexual health, are often diminished or

neglected prior to the start of active treatment. This creates a contradiction: youth and age are hypervisible in the physical space but absent in the treatment of cancer. This is emphasized by Heather (31, white, colorectal), who states, “There are things that I felt robbed of it. My experience was not having a fertility discussion and not even having a discussion about sexual health. But then age being brought up *all the time*, but then it not being considered in the treatment.”

Lindsay (37, white, gyno) locates aberration in the lack of age-specific treatment protocols:

I know we have so many other questions and there are so many things happening that I can't fault [my oncologist] for what happened. It's just the aspect that they don't have protocols for how to treat young adults. They don't have that. It's a gap in service. That's all it is. And that's the shitty ass part of it.

Lindsay articulates a similar frustration between the experience of young adult bodies in medical practice by distinguishing the experiences of pediatric and young adult cancer. She describes how pediatric cancer patients have age-specific treatment protocols and long-term follow-up care plans that "everyone sees" and describes the team approach to treatment absent in the experience of young adults, with "everyone seeing the patient at the same time." She draws a sharp distinction between this experience and that of young adults, "When you go to the adult section, it is just like, "hey, we're just gonna let you fly and throw you out of the nest and see what happens.” Lindsay goes on to describe how she does not have a long-term follow-up care plan, despite her doctors publishing articles on their importance:

My doctor [wrote] in one of the psychology journals a load about the need for a long-term follow-up care plan. Not even long-term, just a *general* care plan.

When one of her patients brought in the article and was like, ‘Oh my God, I want this.’ And she was like, “Sorry, we don't have that.”

Long-term follow-up care plans organize information about an individual's cancer treatment and provide patient-specific information about recommended follow-up care, including frequency of check-ups, testing, and potential long-term and late treatment effects. Long-term follow-up care plans are particularly important for young adults at an increased risk of long-term and late treatment effects (compared with older adults). It is especially important to provide care plans to young adults as many do not continue with follow-up care, and adherence to follow-up care is not predicted by insurance status or disease type (Beaupin, Boldt, and Amato 2018)<sup>7</sup>.

For Eric (34, Black, blood), the lack of research on young bodies was especially salient in relation to guidelines and recommendations for physical activity for cancer patients. Eric describes that while his doctors always encouraged him to "stay active," they defined activity as "going for walks" and "just getting up and moving" rather than "laying in bed all day." When Eric, who performed high-intensity workouts before diagnosis, expressed interest in returning to the gym, his doctors instructed him to practice "exercises for old people." For Eric, the lack of research on young adult bodies and exercise constrained his agency by inhibiting a return to regular day-to-day activities while undergoing treatment. Eric went against medical advice and decided instead to

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<sup>7</sup> Beaupin, Boldt, and Amato (2018) find that almost 40% of young adults do not adhere to long-term follow-up care. My data does not demonstrate the same lack of adherence. This is likely because my sample was pulled from young adults actively involved in young adult cancer-related activities.

"listen to his body," stating that "after working out for so long, I knew when too much was too much." In recalling his experience reentering the world of physical activity, he describes a "disconnect" between medical practice and the limit of what his young body *actually* could do.

In a slightly different case, Donella (41, white, blood) describes their oncologist working to quell the experience of aberration by citing the rapid pace of cancer research and emphasizing that their cancer-type was common and thus thoroughly researched:

My doctor said one of the side effects of my chemo is leukemia in 10 years...He said, "that's ten more years of research, and cancer research is moving really fast now because so many people are affected by chemo. And this [research] specifically because so many people are affected by chemo, right? So a lot of funds go to trying to cure the cancers that people get from the chemo side effects because it's so popular. So he was really clear about the reason why it was good that my cancer wasn't a rare cancer.

In describing the research to cure cancers that occur as a late effect of chemotherapy as "popular," and emphasizing that Donella's cancer "wasn't rare," Donella's doctor is engaging in care work to minimize any experience of aberration by citing the prevalence of both research and incidents of cancer-type in medical practice.

### *Complicating Aberration*

For BIPOC young adults, age and race intersect to shape experiences of aberration in majority-white spaces. Jade (29, black, blood) describes how the store at the cancer center did not carry wigs to match her natural hair texture. "I went to the boutique store before treatment...[where] they have all the different wigs you can look at. None of

them were the right color or texture, they were all straight. It was so frustrating because I didn't get the option to look like myself." Jade's experience is not isolated, as few wigs match Black women's natural hair texture. This is particularly problematic as the wigs purchased at cancer center boutiques are covered by health insurance. This example demonstrates the interplay of cultural and institutional racism (Carter 1995) as straight hair, deemed more desirable and acceptable than natural hair textures, becomes institutionalized into medical practices, creating a differential outcome for Black women navigating hair loss after chemotherapy.

Eric (34, Black, blood) describes how his experience of aberration differed based on whether he was or was not perceived as a patient. He describes feeling increasingly out of place because of his race and age as a young Black man when wearing personal protective equipment. "I am a huge Black dude like covered head to toe wearing masks and gloves... You can imagine the reactions I got, right?". Eric, who has had to take more precautions to protect himself from infection during periods of his treatment, describes how the intersection of his age and race exacerbates his experience of aberration, especially in those spaces where he is marked as a patient. As Eric "never really looked sick," when not marked as a patient, he describes hospital staff assuming he was a "football player coming to the hospital to visit the kids" rather than a patient attending appointments. This assumption by hospital staff reflects the controlling image of Black men as athletes that is central to maintaining White supremacy (Ferber 2007; Collins 2005).

Hector (19, Latinx, blood) experienced out-of-placeness based on language. He describes struggling to comprehend medical information himself and having to piece together instructions with his mother, who is a nonnative English speaker:

My mother has trouble communicating with people... she speaks [some] English, but at the same time, it's difficult for her at times. So, you know, trying to figure out insurance and medical forms, medications, treatment, anything really was just even more difficult for me... Every time they would talk to my mom or me, it would be hard to understand fully.

While Hector was sometimes able to act as an interpreter, his poor health left him "out of it" and, therefore, unable to understand all the information he was given. The Spanish-speaking social worker assigned to the case was not present at the majority of doctor-patient interactions. Medical environments built for English speakers did not sustain or support the full participation of Hector by failing to ensure that medical information was fully understood by himself and his family and preventing him from expressing concerns. Hector's example also demonstrates how the experience of aberration, whether based on medical knowledge or access to an interpreter, squashes young adult agency in the context of cancer treatment.

Some women found that gender intersected with age to create further gaps in medical knowledge, research, and skill about women's bodies. This was often experienced in relation to a lack of medical knowledge and experience surrounding pregnancy, lactation, and reproductive systems. Shannon (36, white, colorectal), who was "warned multiple times that her period would stop or be less frequent" as a side-effect of a particular chemotherapy regimen, experienced the "complete opposite" reaction: "I

started getting my period every three weeks...and it lasted for 14 days". She reflects that her doctors "don't have the data" to understand the impact of chemotherapy on young women's reproductive health: "they just aren't aware that, like not all young women react the same way or [that not all] menstrual cycles react the same way."

There was an overarching failure to consider the impact of treatment on women's bodies. Oncologists failed to acknowledge or minimized side effects like menopause and treatment-induced vaginal stenosis. Alexis (38, white, colorectal) recalls her doctor describing treatment-induced menopause as "not that big of a deal." "I was just getting through surgery and then being told, okay, now you need radiation. And by the way, you're going to be going through menopause." In the following excerpt, she continues by describing the impact of treatment on her sexual health:

Radiation really dries out your vagina. Like I had one period after radiation... I tried to use a tampon, and it was so painful to put a Tampon in because you just lose all of your natural lubricants. It was so painful...after that, it was almost a year before my husband, and I had sex. I don't think I've had vaginal intercourse since I got diagnosed. It just makes sex really hard.

Radiation is a pillar of treatment for colorectal cancer. Unfortunately, a common side effect of radiation is vaginal stenosis, the closing and drying out of the vagina, making vaginal sex painful or, in some cases, impossible. Through his work as a patient navigator Carlos (Latinx, colorectal) has learned that there is an "easy fix" to prevent vaginal stenosis:

Most of these women aren't being told [about these side effects]. They're just being told, 'you need radiation.' Well, there's an easy fix to [prevent vaginal

stenosis], using a dilator during radiation. These women have no idea. And now they're living the rest of their lives, whether they are cured or not, unable to have sex.

Treatment-induced vaginal stenosis is a common side effect in uterine, cervical, vaginal, and colorectal cancers treated with radiation. Despite this prevalence, young adults in my sample, like Alexis, were not offered this “easy fix.” Carlos continues, “you know, we’re all humans. Sex is just something that you get to do. Well, not if you are a woman who was denied that information.”

The intersection of age and gender in aberration was experienced by young adults who were pregnant or lactating. Chloe (34, white, breast), diagnosed at 17 weeks pregnant, describes switching treatment centers after her oncologist and surgeon expressed a lack of familiarity with pregnant bodies: “I didn't feel comfortable with them, having never treated a pregnant woman with cancer before.” Similarly, Amanda (33, white, breast) describes her experiencing out-of-placeness as both a pregnant and lactating body. Amanda recalls that her medical team was unfamiliar with pregnancy-induced breast tissue changes and could not correctly interpret medical images. Amanda also describes that a lack of knowledge associated with experience treating lactating bodies served as an obstacle in locating a surgical oncologist to perform her mastectomy:

I remember hearing the risks ten times over... “There are so many risks that could happen with a lactating mother. I could leave milk behind, which could cause an infection, or I could leave a little bit of [tissue] behind, which could still continue to produce milk.” I mean, I've heard it all. The only thing that I wanted... was the opportunity, like I wanted somebody to take it on and say, “I respect the fact that



you want to breastfeed your child, and we'll do this as long as you understand the risks" and then just move on with it and not be like, I'm not doing this because of the risks.

A lack of medical experience performing a mastectomy on a lactating body made it difficult for Amanda to find a surgical oncologist willing to respect her decision to breastfeed her child before a mastectomy, despite the risk and potential complications. This experience demonstrates the lack of familiarity with lactating bodies in oncology and the lack of knowledge about changes in the body associated with breastfeeding. Such control of women's bodies by male-dominated medical professionals has been documented by feminist scholarship (See: *Our Bodies, Ourselves* 2011). Women's reproductive systems and lactation are seen as aberration in the consideration, demonstrating variation by gender.

### **Consequences of Aberration: Treatment Induced Infertility**

One of the most salient ways that aberration results in a loss of agency is in the loss of reproductive autonomy. This is a particularly important concern for young adults as reproductive behaviors occur in only a portion of the life course, young adulthood. Over half of respondents expressed the lack of bodily control over reproductive choices due to treatment-induced infertility or *the potential* of treatment-induced infertility. Healthcare professionals serve as a key source of information and counsel about the implications of cancer for fertility (Ussher et al. 2016). Previous studies demonstrate that young adults do not receive adequate information regarding treatment-related risk for infertility and available fertility preservation methods (Armund et al. 2015; Penrpse et al. 2012; Peddie et al. 2012; Ussher et al. 2016). Women are less likely to receive this

information, with 48% receiving information about the impact of treatment on fertility, 14% receiving information about fertility preservation methods, and only 2% undergoing some form of fertility preservation (Armund et al. 2015). Cancer survivors often worry about infertility and regret not being offered options for fertility preservation (Barbour et al. 2012). Oncologists do not discuss fertility with patients due to a lack of knowledge, the perception that discussions about fertility preservation will distress patients (Quinn et al. 2009), poor patient prognosis, and time constraints (Ussher et al. 2016). Oncologists also report that treating cancer is more important than fertility preservation (Adams et al. 2013).

When engaging with fertility-related issues, young women across race and class groups experienced similar interactions with healthcare professionals. The majority of young women reported that oncologists did not discuss the impact of treatment on a young adults' fertility, discussed fertility only when asked directly by the patient (often "too late" for preservation to be considered), or failed to provide adequate information about various fertility preservation methods. When the side effects of treatment included a certain or potential loss of fertility were disclosed, options for fertility preservation were presented as nonessential and an unnecessary postponement of treatment. Overall, the overarching narrative offered by young women was that fertility-related discussions were "less than adequate." This is consistent with prior research that demonstrates the problems associated with fertility-related conversations for cancer patients (Armund et al. 2015; Penrpse et al. 2012; Peddie et al. 2012) with medical research calling fertility preservation in cancer patients, infertility treatment among survivors, and the

consequences of reproductive dysfunction a “current challenge” in oncology<sup>8</sup> (Bolaji, Saha, and Sze 2014). The prevalence of fertility-related concerns for young adults was echoed in participant observations.

Underlying the potential loss of fertility is the expectation of *presumed fertility*: that young adult bodies were (in)fertile and that traditional methods of conception would be available to them. Infertility bodies become (dis)abled for failure to reproduce. (In)fertility is often framed as a "choice," such as delaying childrearing while pursuing education or a career. Young adults further reflect this as a loss of control over the "choice" to have children, to control their reproductive future. The expectation that young adults control their reproductive abilities is deeply racialized, classed, and gendered. This loss was expressed by respondents who prioritized having children before diagnosis, those who did not, and those who were already parents. For many, the potential loss of fertility served as a metaphor for a larger loss of agency over one's body.

Heather (31, white, colorectal) and her husband planned to begin trying to conceive shortly before her late-stage colorectal cancer diagnosis. Before commencing treatment, she was given "zero options" for preserving her fertility:

I didn't know that I could do anything. I didn't know I could freeze eggs. I didn't know there was a surgical procedure where they [could move] my ovaries from the radiation range. I had no clue. [My oncologist] basically told me, "you're going to go through menopause, but you're going to be dead in five years if you

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<sup>8</sup>It is important to note that many patient-specific concerns dictate if and what kind of fertility preservation methods are appropriate. These include: “patient's age, cancer stage, proposed treatment regime and time before it is initiated, availability of partner sperm, and issues of individual patients. The latter include surgical complications, ovarian hyperstimulation syndrome, delay in cancer treatment and reintroduction of cancer cells, cost, low success rates and experimental nature of these treatments, and the disposition of gametes if the patient does not survive [their] cancer” (Bolaji et al. 2014).

don't do this." And I was sitting with my mom in that room, and I remember looking over at her, and she said, "I want grandbabies, but to do that, you have to be alive." So I signed the paper. I mean, I was scared for my life, and I came out of it in full menopause, and I can't have any kids. It's one of those things like if you have the choice to choose not to be a parent, you still have the choice. And I feel like I didn't have any choices. I felt like someone reached inside and pulled something out of me without me asking for it. And I felt very, not betrayed, but I felt very violated. Like they took something from me, like something tangible, physical. They took it from me.

Perhaps more illuminating about the loss of fertility is the reaction from young adults who did not plan on having children. Despite the stated decision to be childless by choice prior to cancer, the lack of transparency associated with fertility options was experienced as a challenge to their wider reproductive choices. In this way, failure to adequately address (in)fertility and potential for preservation should be understood in terms of a reproductive justice framework. It is also important to note that access to reproduction has been a central concern of BIPOC women, who have been subject to coercive sterilization and birth control (Roberts 2014).

Despite being diagnosed with reproductive-based cancer, Lindsay's (37, white, gynecological) healthcare team did not explicitly disclose the impact of treatment on her fertility. In recalling her experience with fertility-related communication, she describes her experience as *not knowing anything*. "It was us not knowing anything about [fertility preservation methods] and not knowing what [treatment] meant [for my fertility], not knowing anything." After two years of remission, Lindsay had a reoccurrence that

necessitated a radical hysterectomy. Fertility was addressed for the first time in her "cancer journey" at her pre-surgery consultation while signing medical consent forms. The topic was initiated by her mother, who asked about fertility preservation and egg retrieval. In response, her doctor asked about Lindsay's relationship status, stating that their protocol necessitated retrieved eggs to "already be fertilized." When Lindsay disclosed that she was not in a relationship, her doctor closed the issue, "*it was like 'ixnay' for that, within 10 seconds. It's done without even being discussed.*" Lindsay, who was unsure if she wanted to have children, emphasizes that she is more distressed about losing control over reproductive choices: "that's the part that bothers me more [than the loss of fertility], that it's not my choice. It was taken away from me. It's that aspect of it."

Despite not planning to have children, Jasmin (38, black, colorectal) describes a similar loss of control in response to her oncologist's failure to discuss the impact of her treatment on her fertility: "No I wasn't planning on having any children. But when that is taken away from you, it's like, 'Holy Shit, I can't have children.'" Young adults with children also expressed the loss of control over fertility. For example, Amanda, a mother with two young children, expresses, "I do get a little bit sad every time I think about it. I mean, we're still pretty young and I feel like a lot of our friends are having their third [child] or you know, having a fourth [child] or whatever the case may be. And you know, that choice was taken away from us."

Compared to the experience of women, men were more likely to be offered fertility preservation methods prior to the start of treatment or have fertility preservation built into treatment protocols. This supports prior research findings and is attributed to the relative ease of sperm collection and preservation compared to egg retrieval. Mark

(27, white, blood) recalls how his oncologist integrated the discussion of treatment-related infertility and options for sperm preservation into his first appointment before diagnostic testing had determined the cancer stage or location.: "[My oncologist] said they couldn't guarantee vitality after treatment and that if we were planning on having children in the future, that was a life planning thing they recommended we explore ."For Michael (33, white, testicular), sperm cell retrieval was built into his radical inguinal orchiectomy, co-occurring with the removal of one testicle. He acknowledges that "traditional methods" of fatherhood are "absolutely impossible," stating, "I must be sterile as a bottle of ethyl alcohol from blasting radiation directly in my testicle," but has frozen sperm available if he ever wants to try and have children.

While social and cultural discourses construct infertility as a women's disease and young women were less likely to receive information on the impact of treatment on fertility or engage in fertility preservation methods, not all men could bank sperm before starting treatment. This occurred when fertility preservation could not fit into an "immediate urgency" timeline or because fertility preservation methods were unsuccessful. For example, while Joshua's (33, Black, blood) doctor did encourage sperm banking before treatment, the samples he provided were not viable. This is likely because cancer can decrease the quality of sperm even before treatment commences (Ku et al. 2015). Low sperm counts are especially common in cases of Hodgkin's Lymphoma, the cancer type with which Joshua was diagnosed. Joshua was scheduled to begin treatment within a few days, so he did not have to pursue alternative fertility treatments or sperm collection methods before beginning chemotherapy. While it is challenging to predict

spermatogenesis recovery, and there is a chance Joshua will be able to biologically father children, he describes "accepting" the reality that "fatherhood likely isn't an option."

Eric (34, Black, blood) recalls being told that sperm preservation was unnecessary as his treatment was not associated with loss of fertility, "my doctors said, 'plenty of guys have fathered children on this medicine'." So when his first relapse was detected, he immediately began intravenous chemotherapy, leaving no time to bank sperm:

Knowing the implications [of treatment without prior banking], that I would never be able to father children, that one sort of hit home pretty hard. It was rough. Up until then, my whole dream, the picture of my life, was to have a son and daughter. I'd teach my son how to play catch with a football and have tea parties with my daughter. That was my ideal situation. Having that ripped away from me took away a piece of what I'd hoped for. It took away my manhood.

Normative (heterosexual) masculinity is characterized by able-bodiedness, virility, and the fathering of children (Gurevich et al. 2004; Rome 2021). Reproductive ability is vital to stabilizing gender identity within the cultural context of idealized and compulsory heterosexuality (Butler 1990). For Eric, reproductive failure is framed as an inability to achieve a normative (heterosexual) masculine identity. For young adults, loss of fertility is not just the ability to produce biological children and challenge normative, heterosexual gender identities but also a fundamental shift in how they understand their future --- and even further, their ability to control, to have a choice, on their future. To have that choice taken away—often without informed consent – transforms merely an emotional response, but turns into a visceral, embodied violation.

## Discussion

Young adults with cancer felt as if their bodies were outside the norm and "out-of-place" in cancer centers and medical practice. This aberration was communicated by the medical staff, other patients, and the design of the spaces themselves. It was rare for respondents to encounter other young adults in their cancer center. Out-of-placeness was reinforced by the reactions of clinicians, staff, and other patients, to the presence of a young adult body. Young adult bodies were also outside the norm in medical research and treatment protocols, which were based on the experience of older adults. Lack of available knowledge meant that doctors often expressed uncertainty about long-term survival rates (after 20 years), long-term side effects, and failed to offer young adults long-term follow-up care plans to mediate this uncertainty. I show how aberration results in a loss of young adult agency in the treatment of cancer. I illustrate the consequence of aberration in one particularly salient site: reproductive autonomy.

This chapter explores the implications of aberration in one particular salient site: reproductive autonomy. I find that in decisions about fertility preservation, the locus of agency lies outside young adults. The oncologist decided to preserve or not to preserve fertility. For young men, sperm donation is built into diagnosis protocols. The majority of young women describe having "no choice" to preserve fertility, being "not offered any options" for fertility preservation, and having fertility "pushed to the side." Nonparticipation was evident in the language employed by young women as they assert, "*no one told me*" and "*I didn't know.*" For both young men and women, oncologists determined if fertility preservation was an option; young adults had no real choice except to yield to treatment protocols and their clinicians.



Privilege and oppression shaped the embodied experience of aberration. While most respondents expressed aberration or out-of-placeness, white male respondents commonly articulated distress in their age-based aberration in physical space. This likely occurs because of histories of white supremacy and settler colonialism which have crafted medical systems and institutions for white male bodies. As white bodies are accustomed to the entitlement and privilege of being comfortable in space, this out of placeness due to age was articulated as more distressing. For BIPOC young adults in majority white spaces, race and age intersected in experiences of aberration in physical spaces. Young women struggled with the lack of medical knowledge related to women's bodies, particularly in reference to pregnancy, lactation, and reproductive and sexual health. This aberration challenged women's agency and decision-making regarding parenting and family formation and created long-term consequences for sexual health.

Oncologists were singularly focused on treating cancer and failed to consider the young adult patient in decision-making. This sentiment is expressed by Carlos (32, Latinx, colorectal):

I think that when you are diagnosed, especially when you're younger, most people do want to see you live longer. I use the term '*doctors want to cure you to death.*' As long as you live, anything beyond [cancer treatment] isn't all that important. And that includes psychosocial, mental health, that includes fertility. That includes a lot of different things that aren't discussed when you're diagnosed. This was exacerbated by the use of protocols that did not consider concerns of central importance to young adults, including reproductive and sexual health, which are often diminished or neglected before the start of active treatment. This supports prior research

suggesting that protocols take away the agency of cancer patients, offering an illusion of "choice" that does not exist (Blaxter 2004). I extend this thinking, demonstrating how the construction of treatment protocols based on older adult bodies fails to acknowledge the age-specific concerns of young adults.

It is easy to assume that the misfit associated with young adult bodies results from the numerical minority of young adults with cancer, which accounts for only five percent of the total cancer incidents. This logic is challenged when comparing incidents of childhood and adolescent cancer and young adult cancer. According to National Cancer Institute (2022), around 15,000 children and adolescents are diagnosed with cancer each year compared with 89,000 young adults. More than 90% of children and adolescents diagnosed with cancer are treated at children's cancer centers. These treatment centers are affiliated with the Children's Oncology Group (COG), which maintains strict standards in the treatment of childhood and adolescent-specific cancer care, including treatment protocols and long-term follow-up care. As such, the misfit of young adults with cancer is not reducible to their numeric minority.

The previous theorizing on the body in the era of biomedicine highlights how to experience illness is to occupy a deviant space. It is important to note that, in the space of biomedicine, it is deviant to be sick. Illness and death have been institutionalized and moved outside the space of the home. As such, in many ways, to be sick at all is to be an aberration. I extend this thinking to demonstrate how biomedicine has not only created the context for illness to be an aberration but how this deviance of illness is age specific. For young adults, the deviance of illness as it moves through the world of biomedicine is

more acute and more salient as the spaces construct and reinforce age-specific expectations of ill health in older adulthood.

Research in social work and nursing has identified key experiences of young adults with cancer with particular emphasis placed on experiences of isolation, access to fertility preservation, and financial impacts of treatment. Notably, such studies are often descriptive and designed to provide insight into patient navigators and medical professionals as to the specific concerns of the population. Such approaches are useful, particularly as they demonstrate the concrete needs of young adults with cancer and intend to shape in-house practices. This project moves beyond descriptive discussions of young adult needs to emphasize how bodily expectations are culturally and institutionally informed – and age-specific. I also complicate existing research to demonstrate how the emphasis on the experience of age-based aberration varies based on gender and race.

My findings extend this research, highlighting the underlying bodily experience of aberration as the source of such isolation. While it is true that cancer in young adulthood is less common than cancer in older adults, the visibility of childhood cancers in the cultural imagination demonstrates how this isolation is not purely based on numbers but rather supported (or rather not supported) by medical systems and institutions. While others have identified young adults as needing more ‘support spaces,’ this chapter draws attention to how institutions reinscribe age-specific expectations onto bodies.

Existing literature in medical sociology has given special attention to medicine's approach to women's health, reproduction, and childbirth. This work extends this literature by examining experiences of fertility-related communication and intervention

on young women's bodies. The loss of control over fertility supports previous medical research that labels fertility preservation in cancer patients, infertility treatment among survivors, and consequences of reproductive dysfunction as a "current challenge" (Bolaji et al. 2014). When faced with an off-time illness, healthcare professionals serve as a key source of information and counsel about the implications of cancer for fertility (Ussher et al. 2016).

This research extends this literature by placing emphasis not on fertility per se but rather on control over one's reproductive future and sexual health. In the context of embodied health movements and reproductive justice, physician-related communication is central. This demonstrates the need for informed consent, even when fertility preservation may not be deemed practical. Young adults must be given complete information regarding fertility-based decisions by practical medical personnel.

## CHAPTER IV

### BIOGRAPHICAL AND CULTURAL DISRUPTIONS

“In your sixties or fifties getting diagnosed [with cancer] maybe you’re right before retirement or whatever. But [as a young adult] you’re in the middle of your career, right before a big promotion...right when your life is starting, you know? Right when you're planning to have kids or right when you got pregnant, all these other things and all of that, it just cuts you out at the knees in a totally different way. You don't have a savings account, you don't have a retirement plan, you don't have a 401k, you don't have anything. And then you have to go back to your parents’ [house] and you literally have to become like the kid again.” – *Lindsay, 37, white, middle class, diagnosed with gynecological cancer at 31.*

As Lindsay’s excerpt highlights, the experience of cancer in young adulthood disrupts the life course trajectory in a manner fundamentally different from the disruption experienced by an older adult. Here, I explore how a cancer diagnosis during the young adult life stage impacts young adults' plans, expectations, and everyday life: How does cancer impact future plans and expectations? What are the potentially long-term and cascading effects? How do social institutions work to mitigate or exacerbate the impact of off-time illness? To answer these questions, I focus on two emergent arenas: 1) education and occupation and 2) relationships, intimacy, and family formations. In essence, I seek to understand how the experience of cancer at the critical juncture of young adulthood challenges young adults’ expected trajectories and the potentially long-term consequences of such disruptions.

Biographical disruption is a central concept in the sociological work examining the experience of chronic illness. In this framework, illness is a “major kind of disruptive experience or...critical situation” that disrupts daily life, expectations, and plans for the

future, necessitating a fundamental rethinking of biography and self-concept (Bury 1991; 1982:169). Initially theorized in relation to chronic illness, the biographical disruption framework has been applied to cancer experiences, reflecting the transition of cancer from an acute to chronic illness as survival rates increase. Prior scholarship in this area finds cancer is “disruptive” (Cayless et al. 2010) and “identity-altering” (Mathieson and Stam 1995) with “ongoing physical and psychosocial impacts” (Hubbard, Kidd, and Kearney 2010; Hubbard and Forbat 2012).

Despite this vast application, central critiques of the biographical disruption framework point to its failure to acknowledge how social structure, timing, and context shape experiences of illness. For example, prior scholarship cautions against the universal application of the biographical disruption framework (Faircloth et al. 2004; Pound et al. 1998; Williams 2000). Such perspectives argue that the extent of disruption caused by an illness depends on an individual’s *life stage* and the *timing* of the illness in the life course (Wilson 2007). For example, Faircloth et al. (2004) find that older adults do not experience illness as disruptive but as a natural component of the aging process, consistent with “biographical flow.” Similarly, examining the experience of older cancer patients, Sinding and Wiernikowski (2008) find that older women who endured social hardships were less likely to experience cancer as biographical disruption. Despite the stated importance of timing and life stage, the vast majority of studies utilizing the biographical disruption framework either rely on samples of older adults or heterogeneous samples that include individuals from various life stages. As young adulthood is a transition period, we can assume that the biographical disruption caused by illness during the young adult life stage will be qualitatively different. In this chapter, I

address both these critiques of the biographical disruption framework by focusing on the experience of individuals at one life course stage, young adulthood, and by being attentive to the role of institutions in mitigating or exacerbating the disruption of cancer during young adulthood.<sup>9</sup>

Young adulthood is a period of transition and change (Mortimer and Aronson 2000, Shanahan 2000). As dependence on family declines, individuals begin to establish careers and intimate relationships and assert autonomy from natal family (Seiffe-Krenke 2006). Traditionally, markers of adulthood included completing education, entering the labor force, becoming financially independent, getting married, and becoming a parent (Mortimer and Aronson 2000; Shanahan 2000). However, in recent decades the transition to adulthood is increasingly complex and non-linear (Furlong 2017; Arnett 2011). Young adults are buying homes, getting married, and parenting later than previous generations (Manning 2020).

Cultural and political shifts of recent decades have made young adulthood a life course stage of increasing instability, making it increasingly challenging to achieve the traditional markers of adulthood (Arnett 2011; Furlong 2017). Globalization, technology, outsourcing, the weakening of labor unions, and the spread of neoliberal economic doctrines have resulted in a rise in contingent, precarious, and dependent self-employment. In this hostile labor market employment is insecure and unstable, with limited social benefits (Beck 2000). The emergence of precarious labor markets is central

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<sup>9</sup>I believe that, too often, the emphasis on the individual's experience of illness can serve to *individualize* the critique. Perhaps, given economic changes and the uniqueness of young adulthood, the disruption cannot be understood without examining larger structural forces. In keeping the analysis within Bury's framework, this could be understood as how an individual young adult mobilizes resources to "normalize" the disruption caused by illness. I, however, emphasize institutions not to normalize the reliance on private familial resources. Rather, I draw attention to gaps in societal programs that could otherwise foster resilience in the context of disruption.

to the experience of young adulthood as finding – and maintaining – *secure* employment is necessary to achieve the subsequent markers of adulthood (Furlong 2017). The growth of precarious work has disproportionately impacted young adults who face hurdles in launching careers and experience the highest unemployment and underemployment rates. These patterns persist despite young adults having the highest levels of post-secondary education. Even highly educated young adults struggle to find secure full-time employment that meets their educational attainment (Furlong 2017) and are subject to credential inflation, where jobs require a higher level of education (van de Werfhorst 2009). Recognizing the economic and cultural context of the young adult life stage, I argue that biographical disruptions, at the critical juncture of the young adult life stage, must be understood in terms of their potential long-term and cascading effects.

In this analysis, I focus less on the impact of biographical disruption on young adults' identity (although I acknowledge this often enormous impact) and more on young adults' reports of *how* their biographical trajectories were disrupted by illness and *how* disruptions were mitigated or exacerbated by institutions. Importantly, this perspective emphasizes the role of the institutional environment in shaping the experience of disruption and young adult resilience to illness. I offer the term *institutionally supported resilience* as a conceptual tool to underscore the role of institutions – rather than individuals – in sustained and supportive resilience.

### **Disrupted Biographies and Interrupted Lives**

The biographical disruption framework focuses on how chronic illness disrupts life events and trajectories. A central finding of this dissertation is that an off-time cancer diagnosis disrupts the everyday lives, plans, and expectations of young adults. The age



range of participants (18-39) means that the articulation of transitions and disruptions varied; however, participants believed that illness-related disruptions had long-term implications. Disruptions to the life trajectories were multidimensional, overlapping, and not mutually exclusive, with a disruption related to education and employment cooccurring with disruptions to relationships, intimacy, and family formations. In the following sections, I outline the two most commonly experienced disruptions by young adults with cancer: 1) education and employment, 2) relationships, intimacy, and family formations. For each subsection, I emphasize the role of institutions in alleviating or exacerbating this disruption.

### **Education and Employment Related-disruptions**

Similar to other people with cancer, all young adults experienced disruptions to expectations and plans associated with education and employment with potentially long-lasting implications. While disruptions to education and employment were universal, they manifested differently as respondents were pursuing different goals, at different stages of their professional lives, and received vastly diverse treatment regimens. In the following section, I show how a cancer diagnosis in young adulthood forced respondents to dramatically change how they engaged in educational and work-related activities, reducing work and education hours, leaving university or the workforce, and, in some cases, forcing entirely new educational and career directions. Young adults who continued working had difficulty incorporating treatment schedules with work hours. These findings highlight the importance of flexibility in work schedules, access to short and long-term disability, and the Americans with Disability Act (ADA) protections, including reasonable accommodations. Continued involvement in work and educational

activities maintained a sense of purpose while also maintaining eligibility for health insurance.

The timing of this disruption during young adulthood meant that many respondents were at the onset or upswing of their professional lives, leading some to either pursue the same long-term career goals despite obstacles or reimagine new futures. While a cancer diagnosis in older adulthood likely causes individuals to adjust work and education-related activities, older adults are more likely to have completed their education, have established employment, and may be either retired or nearing retirement age. This timing, at a plateau of professional life, means that activities can likely be resumed more easily than at the critical juncture of young adulthood.

### *Education*

The vast majority of young adult respondents who were enrolled in higher education at the time of diagnosis experienced some form of disruption to their educational trajectories, forcing them to postpone program completion, reduce course load, or withdraw entirely. Hector (19, Latinx, blood) withdrew from community college weeks after the beginning of his first semester. While Hector was eager for the new semester to begin, symptoms of his undiagnosed cancer left him unable to attend the first day of classes. “I wanted to make sure everything was right. Taking the right classes and starting off my first semester right.” He continues, “I didn't even get to go to my first day of college cause the symptoms were initially so bad. I was crying in the morning when I woke up and my mom told me not to go to school and so I didn't.” Over the next two weeks, prior to his diagnosis, he attended classes despite “felt shitty and lost every day” due to pain. Hector was hospitalized immediately following his diagnosis, forcing him to

withdraw from community college a month into the semester. In reflecting on the timing of this disruption, he characterizes the transition into college as the “time to find yourself” and “explore life.” He reflects: “[my friends and I] were entering the real world, you know, finding ourselves...we were figuring ourselves out, what we really wanted. My friends were doing things that I couldn’t do.” Although he was eventually able to reenroll in college, he feels that the disruption of his transition into higher education had long-term implications on his transition to adulthood.

For Eric (34, Black, blood), the physical limitations imposed by cancer treatment upended long-established educational and occupational goals. Eric was preparing for medical school and had an internship at a hospital when he was diagnosed with blood cancer: "Everything changed. Work and school were put on hold because I couldn't work in that setting with a shot immune system." His treatment included a hematopoietic stem cell transplant where healthy stem cells are transplanted into the bone marrow of blood. Unfortunately, stem cell transplants result in the loss of vaccinations, including those needed to work in a clinical setting. While Eric was revaccinated after 18 months, not all vaccinations were successful. "They all took except for the one you should have if you're working in a hospital setting. I talked to my doctors about it, and they said I'd be able to sign a waiver and get back to working in the hospital if I wanted, but they wouldn't advise it just because my immune system is so shot." Eric decided against returning to his internship and declined the offer of admission for medical school. In reflecting on this disruption, Eric states, "life was just beginning...and my entire life and everything that I'd worked for until that point was put on hold."

For Isabelle (26, Latinx, blood), the flexibility of higher education allowed her to

remain enrolled for the duration of treatment by reducing her course load each semester and selectively scheduling her classes. “I was able to schedule my chemotherapy for Fridays [in order to be] feeling better for a Tuesday class.” Similarly, Ph.D. student Shannon (36, White, colorectal), who had completed her coursework, found that graduate school provided a level of flexibility that would be impossible in her prior work experience. “While going through this while doing my Ph.D. is not ideal, it has also fit in better to this lifestyle than it would have if I were working at my old job where you are supposed to be at work every single day. Where here, I can stay home Wednesday through Friday when I'm on chemo, and it's not that big of a deal.” While the flexibility of higher education allowed Isabelle and Shannon to remain involved in educational activities, it was not protective against the disruption of their educational trajectories. For Isabelle and Shannon, a reduced course load extended their timeline to degree completion. The postponing of program completion was particularly troubling for Shannon, who had only five years of guaranteed departmental funding.

### *Employment*

Carlos (32, Latinx, colorectal), diagnosed three months after starting a new job as a stylist, found himself unable to work “immediately” after diagnosis. He describes how his trajectory was “completely interrupted” by diagnosis and subsequent treatment: “I wasn't able to work pretty much immediately. The first surgery happened so quick, and it was very intricate and involved, and then chemo was so hard on me that I wasn't able to work” Carlos remained on disability for two years, during which he describes himself as “sitting at home, trying to get through chemo and trying to heal from all these surgeries.”

Sydney (28, white, blood), who “loved her job,” was forced to take a leave of

absence from work and relocate from her rural town to a metropolitan area to receive care at a large cancer center. In her absence, her company filled her position. While she was promised a job upon completion of treatment, she describes uncertainty over what the position will be:

I'm so grateful that I work for a place that's allowed me to take time off...But on the other side, it's really scary too. I got to pick that job. I applied for it. They selected me. It was something I knew I wanted. I'm going back in and I don't know if I'm going to want it. Obviously, I'm going to take whatever they give me, but it's just kind of weird not knowing what my life's going to look like when I go back to work.

For those fortunate to maintain their pre-cancer positions, some feared their diagnosis would limit their potential for promotion and career advancement. As recounted by Martin (multiracial, 28, blood), "my first thought [after diagnosis] was, I'm never going to get out of this job. I'm going to be the sick kid so they're not going to want to promote me." Martin demonstrates the interrelatedness of an illness-related occupational disruption with a reformation of self-concept and how the perception of self is dependent on others (see: Cooley 1902). Martin develops a self-concept based on how he imagines that he appears to others as "the sick kid."

The decision to leave or reduce work hours negatively impacted the financial well-being and self-concept of many respondents, who, adhering to the cultural expectation of young adulthood, emphasized the importance of both their work and financial independence for their identity. Heather (31, white, colorectal), a self-described "workaholic," asserted, "I've thought about [the impact] on my job more than my family.

I'm hardwired to think about my job." Jennifer (39, white, sarcoma) describes the decision to leave her "dream job" as "devastating on all fronts", "I had my dream job and had to leave it because of this disease."

As young adults returned to work, cancer-related employment discrimination was a key concern. This concern was particularly salient for young adults who were beginning their occupational trajectories and lacked secure (pre-diagnosis) employment, a robust work history, and access to formal (short-term and long-term disability) and informal (offering to "hold" positions) job benefits. Stigma and workplace discrimination are central barriers to employment for cancer survivors (Stergiou-Kita, Pritlove, and Kirsh 2016). Fears of discrimination made some reluctant to disclose their diagnosis and found themselves having difficulty explaining long gaps in their resume or requesting reasonable accommodations at work. Fear of employment discrimination was particularly salient for young adults with metastatic disease who wished to reestablish employment after a period of unemployment.

The rise of social media and the prevalence of sharing one's "cancer story" also created obstacles to overcoming disrupted occupational trajectories, making young adults more susceptible to employment discrimination. Social media usage is common for young adults (Perrin 2015), and many young adults with cancer rely on online communities to connect with other young adults (Perales et al. 2016). In the current internet era, almost 80% of employers often "google" an applicant as part of the hiring process (MacMillan 2013). For those with public social media accounts, cancer blogs, or other cancer-related internet footprints, online cancer stories opened the door for perceived employment discrimination. For example, Danielle (27, white, colorectal),

appeared as a source for a local news story on the rise of colorectal cancer in young adults. This news story remains one of the top “hits” when googling her name. In another example, a Go-Fund-Me was started by the family of Paul (33, white, blood), to help pay for the cost of treatment. The use of medical crowdfunding, where individuals raise money from donors using websites to cover costs associated with healthcare, is rapidly growing to cope with governmental cuts on public health financing (Bassani, Marinelli, and Vismara 2019). While Paul characterizes this money as “essential,” it also “left an online trail” as one of the top results when his name was searched, creating anxiety associated with future job searches. The use of medical crowdfunding (and its potential impact on employment trajectories) disproportionately impacted young adults from working-class backgrounds, like Paul, whose families lacked the financial resources to provide direct monetary support.

Current economic shifts and the rise of a precarious labor market are associated with increased precarity in the young adult life stage (Furlong 2017; Manning 2020). For young adults with cancer, precarious employment exacerbated the disruption of off-time illness. Before diagnosis, Michael (33, white, testicular) describes himself as “just barely” an attorney. After graduating from a prestigious law school during the Great Recession, he struggled to find work and never “had a decent job.” When he was diagnosed with testicular cancer, he worked as a contract lawyer for a large corporation for several years. While this was “good at the time,” it was not a permanent position: “they would keep extending my contract and extending my contract.” As a contract employee, Michael did not have access to benefits like sick time, paid time off, or health insurance. After his diagnosis, he told his employer with very little notice, “I have this

major surgery coming up and I have to do it." While he was taking unpaid time off work, his contract ended and not extended. Michael's experience highlights how an individual's life course is embedded in, and shaped by, time and place (Elder 1994). Graduating law school during an economic recession shaped Michael's employment potential, with him struggling to find stable employment despite his prestigious law degree. As a contract attorney, Michael did not have paid time off or health insurance, benefits associated with traditional employment. Through hospital presumptive eligibility (PE), a key provision in the Affordable Care Act, Michael was able to enroll in Medicaid while seeking emergency care. While Medicaid provides access to healthcare, income restriction limit Michael's return to work:

I made \$28,000, and the Medicaid cap is like \$22,000 or something. So I'm in a weird place, I need to either get a job right now and make a lot of money and start paying for my own health care or I need to stay unemployed and just ride out the Medicaid because I don't have any money in savings, I have barely enough for rent. I have like one more month's rent saved up. I'm really just not working for Medicaid because I'm worried about medical bills.

The disruption of work-related activities did not end with the conclusion of active treatment, and about a quarter of respondents described how the effects of treatment extended beyond the illness period, impacting their ability to perform everyday work-related tasks. The most often side effect cited was "chemo brain," or difficulty with memory, attention, and other cognitive functions following chemotherapy. The impact of chemo brain on the daily lives of participants varied. For example, Shannon (36, white, colorectal) describes difficulty recalling words, "when writing [there] would just be a



word I couldn't think of. For the life of me, I just could not come up with the simplest word.” For others, the cognitive disruption was more robust and enduring. For example, Samuel (35, Latinx, blood) describes the impact of chemo brain on his professional life: "It's not just chemo brain. It is more than that. In my daily life, I know how I am. I know what to expect [from myself]. But what do I do at work when I forget something in the middle of a presentation? I can't just tell my boss that I have chemo brain from treatment a decade ago.” For some young adults, like Samuel, work productivity can be negatively impacted by the long-term physical or cognitive side effects of treatment which reduces earnings and causes distress (Stone et al. 2017).

### *Obstacles vs. Opportunities*

The timing of their diagnosis in young adulthood meant that many respondents were at the onset or upswing of their professional lives, creating long-term and cascading implications for occupational plans and expectations. Those who maintained the same long-term career goals articulated health-status-specific 'bumps', or obstacles in achieving an intended trajectory. These bumps were related to health status uncertainty and the necessity of continued access to medical treatment and long-term follow-up care. Those respondents who maintained consistent long-term goals were highly educated, often in the process of completing graduate or professional education. Graduate and professional students see education as a long-term investment (DeAngelis 1998), and these young adults remained consistent in their long-term goals, despite obstacles, disruption, and delay. In one case, Ph.D. student Shannon (36, white, colorectal) maintains the same long-term goal of becoming a full professor but describes how, because of her diagnosis,

"the path to get there is longer and filled with more anticipated bumps in the road." In the following excerpt, Shannon describes these bumps:

It's not like, *oh, I didn't get that grant bump-in-the-road*, it's the *oh, I can't start my fieldwork until three to six months after I planned on starting it or I'm going to be out for a month because I'm having liver surgery*. And when I'm looking at where I want to work, I also have to keep in mind where I want to get treated for cancer and worry about what will happen if I cannot work for some time [because] my husband's [job does not provide] health insurance and my only source of insurance is through my work. So it definitely puts the things that you might normally think about as being a bump in the road in perspective. But, at the same time, on some level, on a day-to-day basis, it's not that different from dealing with those like smaller typical bumps. It's just that they *keep coming* for a greater amount of time and you just have to adjust to them. Which has been the hardest part for me because I'm not great at letting go of a plan.

As Shannon's quote highlights, the path to – and timing of – her long-term plans is thrown into question. She distinguishes the setbacks typical of academia, failure to secure funding, and the bumps that she anticipates experiencing: the postponement of teaching and research activities, an increasingly selective job search, access to treatment, and the importance of maintaining health insurance. For Shannon, the disruption to her long-term plans means she has to make contingencies, not the removal of the goal itself: "I definitely think about the how-do-I-get-there and the contingency plans a lot differently, but I still think the desire is the same. Like the this-is-what-I-want-life-to-be-like is the same."

In another example, Lindsay (37, white, gynecological) points to health care policy as an obstacle to becoming a licensed therapist. As she explains, it is common to accrue the practicum experience necessary for her professional licensure by working several part-time jobs simultaneously. These part-time jobs do not include benefits like health insurance. Lindsay must meet strict restrictions on her yearly income to continue qualifying for Medicaid, the means-tested and needs-based program where she receives health insurance. Working multiple jobs will result in an income that exceeds the maximum Medicaid limit. In the following excerpt, she reflects on this obstacle:

I didn't make this choice; this choice was made for me. I would 100% love to have 15 part-time jobs so I can accrue a lot more hours but I cannot because then I don't have health insurance and I cannot then be treated at my hospital. Right now, being treated at my hospital is a little bit more important. Continuity in care is more important to me than this diploma.

While she can receive health insurance through the Affordable Care Act exchange, none of the ACA plans are accepted at the cancer center where she receives treatment.

Unfortunately, this is not uncommon, as National Cancer Institute (NCI) cancer centers only accept 59% of networks on the ACA exchange (Kehl et al. 2017). Access to NCI cancer centers is especially relevant for young adult patients like Lindsay, who often benefit from specialized cancer care (Barr et al. 2016; Wolfson et al. 2014, 2015).

For a minority of respondents, disrupted plans were reframed as new opportunities, providing the time, space, and social networks to transition into "something better." In these cases, young adults were at the beginning of their educational trajectory, just entering the workforce, or unable to meet the requirements of their previous plans. For

example, after Eric's (34, Black, blood) cancer diagnosis left him unable to attend medical school or work in a clinical setting, he "[accidentally] fell into the world" of web development and graphic design. While receiving treatment in the hospital, Eric stayed mentally active by helping design a friend's website. As he describes, these learned skills, paired with contacts made through cancer support groups, would serve as the launching point for the creation of his own company:

I knew the basics of [website design], but I didn't fully know how to get [a website] up and running from scratch. Every morning [while in the hospital], I'd have my laptop working in my bed...[The website] took a couple of months to complete. A few months after that, I ended up going on a retreat for men with cancer. We'd always have conversations after dinner, and the topic one night was, *'what's something you've had a chance to do that you wouldn't have if it weren't for cancer.'* And so I started telling them about the website I built for my buddy. And after that conversation, the head guide comes up, and it's like, 'hey, we could use some help with our website. Can you help us out?' I was like, sure, no problem. A few months later, I was on a trip with a [current] client, and a similar conversation came up and afterward they asked me to rebuild [their website].

While Eric's educational trajectory was disrupted, he used the time to immerse himself in a new field. His involvement with cancer survivor organizations gave him a social network of potential clients that helped him "gain traction" and turn this freelance work into a successful company. In reflection, Eric describes this transition in a positive light, satisfying his desire to help people. "My career path has definitely shifted, but I think it is a good thing...A lot of the companies I work for are nonprofits that have something to do

with cancer.” He continues, “I want to help them grow and reach survivors like me, who are lost and in the hospital, wondering what's next with life. So I'm still helping people, but there's a different means relative to how I help them.” Eric’s experience demonstrates how the disruption of educational and occupational trajectory can be reframed as an opportunity to help others with cancer. This desire to help others, termed "altruistic adaptation" (Little et al. 2000) is common to the experience of survivorship. Highlighting the desire to help others via altruistic adaptation provides meaning to Eric's illness experience and is a way of coping with his biographical disruption (Bury 1982).

Notably, some young adults described a desire to change paths following cancer diagnosis but were constrained by the unique features of young adulthood and a dearth of social support, particularly for young adults. For example, Jeremy (36, white, blood) describes how his desire to change occupational trajectories post-treatment is constrained by the fear of recurrence and the necessity to maintain access to employer-based benefits like health insurance:

I feel trapped in the path I chose before diagnosis and beholden to the relationships and commitments I had made. So sometimes I ask myself, *'why can't I just jump into something new?'*... But reality hits me, and I think about insurance, short and long-term disability, [supporting my] family, and what it really takes day in and day out to keep going if I ever had a recurrence. It's crushing anxiety...[so] I avoid thinking about a career change most of the time.

### **Relationship, Intimacy, and Family Formation**

All young adult respondents experienced some form of disruption to the relationships that preexisted their cancer diagnosis; preexisting relationships were

renegotiated and dissolved, and new relationships were cultivated based on shared experiences. In the following section, I demonstrate the impact of a cancer diagnosis in young adulthood on 1) family formation (partners, marriage, and parenting), 2) natal family relationships, and 3) friendships. These disruptions are not mutually exclusive. While all respondents experienced at least one disruption, many were experienced simultaneously. In examining these disruptions, I demonstrate how a cancer diagnosis during young adulthood can have long-term implications on relationships, intimacy, and family formation that extend after the initial disease period has ended. While the experience of relationship strain is not unique to young adult cancer patients and survivors, older adults are likely to have more established relationships that may be better able to withstand disruption.

### *Natal Family*

Most young adult respondents reported disruption to the natal family due to a cancer-induced renewed dependence on parents and, thus, the loss of previously achieved markers of adulthood. While a life-threatening illness often results in loss of independence, cultural expectations of independence in young adulthood may make this loss more distressing for young adults with cancer. It is becoming increasingly difficult for young adults to achieve the traditional markers of independence. For many young adult participants, the level of independence, albeit varying, achieved prior to diagnosis was fragile and unsustainable through a life-threatening illness. In this context, the natal family served as an invaluable source of support for young adults who are otherwise outside of most age-based supports (based on the transitional phase of young adulthood) and lack resources of their own. In the following analysis, I discuss the two most

common sources of disruption to the natal family: financial independence and living outside of the parental home.

As most young adults, irrespective of social class and insurance status, lacked robust savings to finance the financial burden of cancer, many families “filled the gaps” by providing financial and material support.-In these cases, young adults continued to live independently but received support from family to cover medical bills and living expenses. The timing of cancer in young adulthood matters as children are not expected to be financially independent, and older adults would likely have more financial security and resources to draw upon or qualify for age-specific social support like social security or Medicare. At the same time, young adults describe financial independence as a central feature of adulthood (Arnett 1994, 1998). Thus, accepting financial assistance often served as a source of distress. While there was vast variation in the kind of support provided by the families of young adults, patterns emerged based on social class. Upper and middle-class families were more likely to provide young adults with direct financial support. In contrast, working-class families bought groceries, provided meals, and organized community fundraisers to support young adults.

Monica’s (28, white, thyroid) middle-class parents filled the gaps caused by her underinsurance, paying all her medical expenses, including the cost of her out-of-network doctor. “My parents had a lot of money to the side [in case] something like this happened.” Self-employed, Monica describes having limited access to quality health insurance. “I’m not a part of a huge insurance company because I’m self-employed [and I] cannot get great insurance like [I could] through an employer.” In order to access the care she needed, Monica had to go out-of-network to a provider not covered by her insurance

policy. Monica's parents "foot the bill" for her care and two surgeries by drawing on personal savings. "My parents are more than happy to foot the bill for that. They don't want me to be like, '*oh, I'm sorry, this is a lot of money.*' They want me to feel comfortable and safe and like I have control of everything more than stressing about the cost of a surgery."

Heather's (31, white, colorectal) middle-class family provides support by helping to pay her mortgage and putting money directly into her checking account. Unlike Monica, whose parents had savings to draw upon, Heather's parents lacked the financial resources to help outright and opted instead to delay retirement: "My mother, she got a second job so that they could take care of us. So they are putting off their retirement to help their daughter." Heather's experience is unique, as it demonstrates how the disruption to Heather's work trajectory also impacted her mother's work trajectory (the delay of retirement). While Heather is thankful for this help and recognizes the privilege associated with avoiding what she refers to as the "collateral damage" of cancer, she describes the negative impact of financial independence on her self-concept:

Especially as a young person, you're making all these big plans. And then I have to go from there to being in a situation where you're dependent upon [parental] financial support again. That's really tough. I feel like we just got our freedom. We bought a house. We bought two cars. We were kind of doing that start-out thing, *we're really nervous cause we might not be able to afford everything, but we're going to work really hard.* Then I get sick and I'm like, okay, yeah. Oh my gosh, I've to go back to my mom.



For Heather, the disruption caused by cancer occurred at a critical juncture when she and her partner were just "starting out" and gaining their "freedom." As such, she articulates not only a disruption to her expectations and future plans but also the disruption of her culturally assumed pathways to adulthood: financial independence.

Finally, Alexis' (38, white, colorectal) working-class family provided support by putting on a community fundraiser. "When we got that diagnosis, we were scared about [losing the house]. You know, my husband was like, we'll sell the house." Financial necessity forced Alexis, who had not disclosed her diagnosis to many people, to go "public" with her cancer. "I was apprehensive about putting the fundraiser on social media, but I did it because we really did need the money." She describes the outpour as "incredible," providing an invaluable level of security in an uncertain time . Reflecting on this support, she states: "Some people are like, always one step from disaster. I don't feel that way. I don't feel like we're gonna lose our house or anything, but, you know, it is possible." Alexis' example illustrates the precarious position of young adults, who, based on the transition phase of young adulthood, lack financial resources and how the family is central to the engineering that facilitates young adults' resilience to this financial disruption.

Cancer forced some young adults who did not cohabit with a partner to move back into the family home because they could not afford the cost associated with living independently due to reduced employment or the high cost of medical care (as those with partners often lived in a dual-income household). While it is important to note that access to a spare bedroom is a marker of class privilege, this pattern occurred across all class levels.

After leaving work, Danielle (27, white, colorectal) moved back home to her family home. While she qualifies for disability benefits, the payments were insufficient to cover her out-of-pocket medical and living expenses. Acknowledging her need and gratitude for the "help" provided by her parents, Danielle expresses disappointment and discomfort in her loss of independence and "being treated as a kid." Similarly, for Rebecca (34, white, breast), moving home challenged self-concept: "it's weird to be an adult and feel like a sick kid." Like Danielle, Rebecca is thankful for the care provided by her mother, who brings her Gatorade and saltine crackers, but struggles to acclimate to her loss of independence. In a dissenting experience, Jennifer (39, white, sarcoma), who has moved back to her parent's house numerous times in the 19 years since her diagnosis, describes her parent's home as a "magical place," drawing a contrast between her experience and the experience of newly-diagnosed peers. "I have friends who are like newly diagnosed and facing the fact that they may have to move back in with their parents, and they're just like, *it's so embarrassing*. I'm like, I love it. Parents make coffee every morning at six, and they have breakfast. It's like a magical place!"

Young adults asserted agency in the context of natal relationship disruption by engaging in emotional management to "protect" parental emotions, reasserting independence, and rejecting financial aid. In one instance, Martin (28, multiracial, blood) describes how he filtered the information given to his mother before disclosing his cancer diagnosis, "I wanted to know the full situation and be able to break it down into terms that would not make it seem as bad as it was because she's really emotional and I knew if I broke the news over the phone, she would freak out." Mariana (38, Native, colorectal) describes "shielding" her large family by selectively sharing information. For Mariana,

whose case is likely terminal, selectively sharing information is a way to reassert agency and protect herself from emotional labor. “The women all tell the men, and my grandma, I call her the mouth of the south. You tell her something and she'll tell anybody... I get so emotionally drained, you know, it sounds stupid, but even having to text, I feel so drained.”

Hector (19, Latinx, blood) describes his resistance to what he sees as overly-attentive mothering and limitations on his freedom:

Ever since I was diagnosed, my mom and I have been spending so much time together. We slept in the same room together. She would constantly worry about me, check up on me, and tell me what to do... I wasn't allowed to go out with my friends or anything when I was at home, and that just pissed me off, and I would just go out anyway.

Michael (33, white, testicular) resisted the financial assistance from his parents and felt "conflicted" knowing that his parents could be used as a "backup" if necessary: "I don't have any money in savings, I have barely enough for rent. I have one more month rent saved up... but I don't want to [get money from my parents]. I'm a grown ass man.” For Michael, accepting financial help as a "grown-ass man" disrupted the cultural expectations of independence and self-reliance during young adulthood.

### *Family Formation*

For about three-quarters of respondents, the timing of cancer in young adulthood disrupted family formation, including romantic and sexual relationships, parenting activities, family planning, and fertility trajectories.

Young adults complained that their cancer diagnosis negatively impacted romantic and sexual relationships. This encompasses the disruption of relationships established before diagnosis, during and after treatment, and the perceived disruption of future relationships. Relationship disruption was exacerbated by financial strain and caregiving responsibilities. Many who were single when interviewed expressed anxiety about entering new relationships and feared long-term side effects, like scarring, changes to sexual functioning, or treatment-induced infertility, would make them less desirable to potential partners.

Unmarried partners were more susceptible to separation following a cancer diagnosis. Eric (34, Black, blood) characterizes his diagnosis as “the straw that broke the camel’s back” with his long-term girlfriend, and Brittany (35, white, sarcoma) describes the dissolution of an 8-year relationship because her partner failed to provide the necessary support: "I was extremely ill, and I needed help and I didn't get it." Respondents who were married at the time of diagnosis described similar cancer-induced strain but were more likely to be “working” on the relationship. At the time of the interviews, no marriages had ended in divorce. This may be because cohabitation is less stable than marriage (Van der Vliet 2020).

The financial strain of cancer exacerbated relationship strain. Chloe (34, white, breast) describes how her husband had to "take control" of their finances, working 60 to 70 hours a week, to cover high medical bills and compensate for her lost wages.

He worked so many hours to provide for us and provide security because I had to have a ton of time off work and all of these medical bills and all of this stuff. So he wasn't around to help because he worked 60 and 70 hours a week and, you

know, at least 12-hour days. So he was not home. He was just not there. And so I think there's definitely a lot of effects from that, a lot of issues that have stemmed from that, from communication breakdowns to intimacy breakdowns, which is nonexistent at this point. And just, you know, we kind of feel like we're glorified roommates if that is even a term.

Through marriage counseling, Chloe has learned that her husband felt “cast to the side” throughout her diagnosis and treatment and the impact of the added financial burden of cancer. Narratives of infidelity, divorce, and relationship troubles were so prevalent in the young adult cancer community that one respondent, Amanda (33, white, breast), describes limiting her involvement in social media groups that were "making [her] paranoid" in her marriage.

Disruption to intimate relationships also occurred when the side effects of treatment negatively impacted sexual relationships with both long-term and casual partners. As a life stage, young adulthood is associated with peak sexual functioning and reproductive health. Respondents that experienced treatment-induced changes to sexual functioning and reproduction challenged this societal expectation.

In one instance, Heather (31, white, colorectal) describes how her treatment impacted her sexual relationship with her new husband:

There's no way to be intimate...and I mean, we're newly married, so this was a big part of our relationship, and it just quit overnight...all of the [side effects] of radiation caused painful intercourse. And we're sort of at this point where I think he's afraid to touch me because he doesn't want to hurt me.

While it was common for cancer treatment to disrupt sexual relationships, it was not universally experienced by young adults. For example, Donella (41, white, blood) characterizes their sexual appetite as "insatiable" during chemotherapy, and Carlos (32, Latinx, colorectal) describes how he and his partner "got creative" to maintain their sexual relationship.

For young adults who had not all achieved their parenting goals, a cancer diagnosis challenged plans for childrearing and parenting. Mitch (42, white, blood/sarcoma) demonstrates how a cancer diagnosis results in an expedited fertility trajectory and a disruption from personal parenting ideals. After he was diagnosed at 28, Mitch received oral chemotherapy for a year while a bone marrow donor was identified. While oral chemotherapy did not impact his sperm quality, bone marrow transplants often cause infertility.

While waiting for a donor definitely did speed up our plans to have children. My wife and I talked about it between that crisis point and the bone marrow transplant. We're like, do I save my sperm? Do we just go ahead and have kids? And so we made the decision to start trying to have children ended up my wife ended up getting pregnant with twins. My wife gave birth one week before I went into the hospital for my bone marrow transplant.

Young adults expressed concern that treatment-induced infertility would make them less attractive to potential partners. For example, Jasmine (38, Black, colorectal) describes:

So I'm a young adult...at some point, I'd like to get married. You have to think about having a conversation with a spouse or somebody who could potentially be

a spouse and saying, "I won't be able to give you kids." I mean that's a whole new level of emotion that I had never thought I'd ever have to express.

These concerns are valid. In one instance, Eric (34, Black, blood) described when a potential girlfriend ended the relationship because of his treatment-induced infertility. "[She told] me, 'no, this just isn't going to work out' about the kids and cancer. She was very nice about it...[but] I cannot give her what she wants and there's no way around it." Eric demonstrates how the inability to father children strains his self-concept, making him feel like "less of a man." This is consistent with previous research that connects fathering children and hegemonic masculinity.

Such experiences of relationship disruption made some young adults reluctant to enter new romantic relationships. After struggling with losing both a long-term partner and friendship group, Jennifer (39, white, sarcoma) states, "I don't even try, you know, people don't volunteer for this. Healthy people aren't beating down your door." Jennifer expresses something important: it is not just the disruption of existing relationships but the disruption of relationships that may occur in the future. She states that "[healthy people] do not volunteer" to establish relationships with someone who experiences the instability of an off-time illness. Others expressed a similar hesitancy to enter into romantic relationships: "Everything is fragile for me. I don't have any time or any energy for [a romantic relationship]" (Rebecca, 34, white, breast). Returning to the experience of Jennifer, who was diagnosed with a slow-growing sarcoma at 19 and has "never been in remission" and undergone various treatments over nineteen years, describes difficulty maintaining romantic relationships when her "primary relationship" is to her illness:

My primary relationship is to my illness. It's not always, but it is for whole years [at a time]. It can be really hard to be dating someone when that's the case. It's also hard to believe that anyone would take your faults and all when your faults include \$80,000 in medical debt and a lifetime of chemotherapy.

While the experience of cancer likely incites relationship disruption in older adults, older adults are more likely to have established friendships and romantic partnerships that may be less vulnerable to such strain.

Disruptions to romantic relationships were not universal, with a minority of respondents describing strong partnerships throughout diagnosis and treatment. For example, Mariana (38, Native, colorectal) describes her partner's invaluable role: "She's always like, '*you gotta take your medicine, you gotta do this*'... Anything I need, she's there, you know, she takes me to all my appointments. She drives me anywhere I need to go. If I'm not feeling good, she'll drive me. I'm so grateful that she's able to do that and that she's even stuck around for that."

### *Friendships*

The most common form of relationship disruption, expressed by the majority of young adult respondents, was a dramatic disruption to friendships. In young adulthood, friends are essential, replacing parents as confidants and attachment figures that provide validation, support, and emotional support (Wrzus et al. 2017). Young adults felt "left behind" by friends as peers progressed through life without illness-related disruptions. As Hector (19, Latinx, blood) expressed, "I felt like my friends were getting ahead in life while I was being set back." In other instances, the disruption of friendships was characterized by interviewees as friends "not understanding," "not knowing how to talk,"



or failing to “provide support” for young adults experiencing a cancer diagnosis. As young adults found themselves moving backward, or stagnant, in education, occupation, and family formations, they watched “friends progressing so much farther”: “Everybody is just at different places. I’m at a totally different place... and you cannot explain that” (Danielle, 27, white, colorectal). This retardation, perceived and actual, resulted in some young adults pulling back from existing relationships. In one example, Maria (26, Latinx, blood) expressed frustration that, as her friends continued to “move forward” and achieve traditional markers of adulthood, she was reminded of the disruption to her own trajectory and imagined future: “I saw all my friends getting jobs, getting married, having babies... And me, I’m not doing anything.”

Respondents were surprised that long-established friends “dropped off” at various points along their illness trajectory. For example, when Heather (31, white, colorectal), called her best friend to tell her she had cancer, her best friend hung up on her. “She told me that she felt really bad, but she just couldn’t process what was going on with me because her life was too busy. She couldn’t deal with her own life much less mine.” Despite being close friends for so long, their friendship never recovered. “It’s really sad that that friendship is no more... She is someone that I thought I could trust to help me through this, and to not have her has been hard.” In other instances, networks of friends that were initially very supportive became exhausted over time, leaving the young adults feeling increasingly isolated. These feelings were particularly salient after the conclusion of treatment when young adults moved out of active treatment. Some participants felt they could not express concerns and fears associated with their illness: “I don’t always feel comfortable expressing my emotions to some of my friends. It seems as if they’d like

me to get over it." Monica (28, white, thyroid) describes wishing her friends offered more support.

It makes me a little bit angry and a little bit, honestly embarrassed, because I was getting support from my friends and the way that I put it to them was, "Oh, it's the good kind. They just do the surgery and that cures everything." So they kind of digested it as, "*Oh, she's gonna be fine and live a normal life*". Not that I wanna live with people's pity, but I kind of wish I could redo it to introduce it to them as something that is going to be a big stressor in my life.

As she was diagnosed with a "good" cancer, her friends fail to recognize the ways that her illness continues to be a "big stressed" in her life.

While the disruption of friendships was a common theme throughout the interviews, some young adults experienced strong support from existing friendships, and others forged new friendships based on the shared experience of cancer. For example, Isabelle (26, Latinx, blood) characterizes her friend group as "really close" and describes her friends as "constantly" with her throughout treatment: "[my friends] were always there for me. They visited me as much as possible even when I was just sleeping." Others described cancer as helping them "get rid of the dead weight" and establish more meaningful relationships with a few long-term friends.

In response to the relationship disruption due to an off-time cancer diagnosis, many young adults sought friendships within the young adult cancer community. For example, Rebecca (34, white, breast) describes that, while her "healthy friends have not done a thing" following her double mastectomy, the "community of cancer [has] stepped up." Likewise, Jennifer (39, white, sarcoma) describes how finding a community of other

young adults with cancer provided a level of (emotional and instrumental) support and understanding absent from friendships with non-cancer patients and survivors:

I have many friends here, but they will not fucking [take me to medical appointments] because they do not believe that I'm sick or they don't understand the gravity of it, and [young adults with cancer] all do. I had never walked into a room full of people to whom I didn't have to explain anything. I didn't have to explain why I didn't own a house and then have to explain why I wasn't married and didn't have kids. I didn't have to explain why I didn't have a fucking 401K. They all knew; they all knew why. And that was a unique experience for me. I've never felt that and I am so glad I have it now.

## **Discussion**

This chapter explores young adults' experiences of biographical disruption in the context of an off-time illness. A biographical disruption occurs when a cancer diagnosis disrupts a young adult's daily life, expectations, and future plans. Key sites of young adults' biographical disruption were education and work, and relationships, intimacy, and family formations. Young adults shared disruption in these sites despite variations in diagnosis, treatment, and diverse positionality in the trajectory to adulthood. In this study, both the disruption and a young adult's resilience to disruption were impacted by social institutions, or what I term *institutionally supported resilience*. Notable institutions included social welfare programs, healthcare systems, educational systems, and the family. As the successful transition into adulthood is predicated on completing education and entering the labor force (Mortimer and Aronson 2000), my findings demonstrate that cancer in young adulthood disrupted these culturally assumed pathways to adulthood.

It takes a great deal of time to be diagnosed and treated for cancer; young adults find the time commitment of cancer challenging to incorporate into most full-time work and school schedules. To cope with the side effects and time commitment of treatment, young adults reduced work hours, went on leave, or withdrew entirely. For young adults who were employed, a cancer diagnosis resulted in a total or partial loss of income and wages. Young adults who were pursuing undergraduate or graduate education often had more flexibility built into their schedules, but this flexibility resulted in longer timelines and delayed transition into formal employment.

The experiences of young adults demonstrate the potentially long-term, cascading impacts of the disruption to educational and occupational plans and expectations. The timing of this disruption during young adulthood meant that many respondents were at the onset or upswing of their professional lives. Young adults with no established work history faced difficulty navigating the stigma of labor-market disruptions and the stigma associated with their health status. Those with established employment feared that their illness might result in a lack of advancement. Some young adults continued to experience cognitive side effects that negatively impacted job performance long after the conclusion of active treatment. In response to the biographical disruption, some young adults on the brink of their professional careers maintained the same long-term goals despite obstacles. In contrast, others reframed disrupted plans as opportunities to transition into something better.

Cancer treatment and diagnosis disrupt relationships, intimacy, and family formation. Every respondent experienced some disruption; preexisting friendships and romantic relationships were ended, renavigated, and in some cases, strengthened. The

experiences of young adults demonstrate the potentially long-term, cascading impacts of disruption on plans and expectations. Young adults who were single when interviewed expressed anxiety about entering new relationships and feared long-term side effects, like scarring, changes to sexual functioning, or treatment-induced infertility, would make them less desirable to potential partners. As many young adults had not yet attained their parenting goals before diagnosis, the potential of treatment-induced infertility negatively impacted reproductive trajectories. Notably, the decision to preserve or not to preserve fertility was made by the oncologist rather than the young adult. Young men were more likely to have sperm donation built into existing medical protocols, while most young women described having "no choice" to preserve fertility.

The disruption to paid employment was central to the disruptions of the natal family. The partial or complete loss of income and wages cooccurred with out-of-pocket medical expenses. Without full wages, young adults lacked robust savings and assets to cover the costs associated with medical care and living expenses. The natal family was central to the engineering that facilitated young adult resilience to an off-time illness for those otherwise outside of most age-based supports and lacking resources of their own. Upper and middle-class families provided young adults with direct financial support, while working-class families relied on community fundraisers to support young adults. While essential, this renewed dependence on parents negatively impacted the self-concept of young adults as it challenged cultural expectations of independence.

In many ways, these findings align with prior literature examining parental support of adult children. Prior research demonstrates that parents often provide financial, housing, and emotional support (Newman 2012; Fingerman et al. 2009; Sandberg-

Thoma, Snyder, Jang 2015; Swartz, McLaughlin, Mortimer 2017; Swartz et al. 2011). While not always distressing for young adults, parental financial help is associated with depressive symptoms for young adults who have already moved into adult roles (Kirkpatrick Johnson 2013). Newman (2012) documents how present economic uncertainty results in "accordion families," where adult children live with their parents. Newman (2012) also finds that countries with more robust social welfare systems have fewer accordion families, as unemployment, healthcare, and affordable housing, allow young adults to be more financially independent. I build on this work, finding that the "boomerang," where young adult children move back into the natal home (Newman 2012) and the necessity of financial support, is exacerbated by gaps in the social safety net for young adults in times of illness. Importantly, in my sample, young adults had established independent living and employment pre-diagnosis, making the disruption even more challenging to self-concept.

Prior research demonstrates the rise of medical crowdfunding to cover the cost of medical care, emergency treatment, exploratory therapies, and medical research and development (Snyder et al. 2016; Bassain et al. 2019). This rise has been attributed to governmental cuts on public health financing (Bassain et al. 2019). While not generalizable, my findings demonstrate that working-class young adults *with insurance* use medical crowdfunding to cover the costs associated with treatment and lost wages. The reliance on crowdfunding created a perceived obstacle to employment activity due to online visibility. According to Microsoft, almost 80% of employers view online information about potential employees (MacMillan 2013). Further studies show that medical crowdfunding replicates patterns of racial inequality, with Black and Latinx

beneficiaries receiving less money than their white and Asian counterparts (Igra 2022; Igra et al. 2021) and redirecting public attention away from growing gaps in the social safety net (Berliner and Kenworthy 2017).

Young adult resilience to employment disruptions was mitigated by robust workplace benefits, including health insurance, access to short and long-term disability, and workplace flexibility. The rise of contingent and contract labor meant that access to these benefits was uneven across young adults. Key policy changes included in the ACA supported healthcare access, particularly the Medicaid expansion, Hospital presumptive eligibility (PE), and coverage for preexisting conditions. Jennifer (39, white, sarcoma), diagnosed prior to the passing of the ACA states: “The Affordable Care Act was the only thing that was going to save my life, not my finances. There is no way that a human could salvage my finances but save my life. And the reason that I was going to die was because I couldn't afford healthcare.” While these programs improved access to healthcare for young adults without health insurance, income restrictions made it difficult for them to return to work. Young adults made future work-related decisions based on the need to maintain health insurance, impacting future employment decisions.

Previous research demonstrates that stigma and workplace discrimination are central barriers to employment for cancer survivors (Stergiou-Kita et al. 2016), and it can be challenging to attain the necessary accommodations to return to work (Stergiou-Kita et al. 2016b). Even when a young adult had completed treatment and had "no evidence of disease," the mark of an off-time illness on their biography impacted how young adults perceived their employment potential. As such, it is not just disruption of educational and occupational activities that creates potentially long-term impacts but also the stigma

associated with severe illnesses, even when long-term side effects do not occur. Stigma is a cultural concept that reflects cultural norms and values that (re)produces inequality (Parker and Aggleton 2003). The stigma of off-time illness is not an attribute of an individual young adult but instead reflects the dominant cultural expectations of health and productivity for young adults in the labor force.



## CHAPTER V

### STRATEGIES OF ACTION IN UNSETTLED LIVES

“If you say, ‘oh, I've had cancer twice.’ There you go. You're automatically labeled with, ‘*oh, you survived cancer twice. You must be this larger than life person*’... And in actuality, I just feel weak, and I feel tired, and I feel like the world has this expectation for me to be this amazing person to go out and do amazing things. And I can't yet. So that's probably a part of why I'm sitting here taking stupid antidepressants. Cause I can't figure out how to get off my ass and go off and save the world. – *Robert, 42, white, diagnosed with blood cancer at 28 and a secondary treatment-related sarcoma at 42.*

“Arrested development, if you will. Just stuck in that moment of being a 26-year-old trying to figure out life. And here we are eight years later, and I'm just trying to figure it out, making the most of every situation, trying to make it a better one. And I realize that [cancer] is always going to be a part of my story. This is me for the rest of my life... I'm just in a constant state of trying to figure things out and I'm just making it up as I go along. But it's all within this filter of 'you have cancer,' right? I have cancer... So how do we move beyond it and do something meaningful? It's, I don't want to use the word paralyzing because it's been empowering. The situation has been empowering for me, but, um, yeah, it's just trying to figure it out. – *Eric, 34, Black, diagnosed with blood cancer at 26.*

I begin this chapter with the admission that it was the most difficult to write. As my last empirical chapter, this should, in a sense, "conclude" the experiences of my respondents. Through these pages, you have come to know my interviewees through their own stories, moments of their lives as they pass from the world of the healthy to the world of the sick. Unfortunately, I offer no conclusion to these stories. For my respondents, cancer and its impact do not conclude. In many ways, it is this enduring characteristic of cancer in young adulthood that inspired this dissertation. A young adult may be “cancer free” or have “no evidence of disease,” but cancer is not something that they “get over.” Frank (2013) conceptualizes this as “remission society,” where those

with cancer linger between the world of health and sickness. Little et al. (1998) term this a space of “liminality.” It is in this space that young adults “figure out” life after a cancer diagnosis.

Thus far, this dissertation has examined the experience of a cancer diagnosis in young adulthood. An underlying theme throughout these chapters is that an off-time illness *unsettles*. Off-time illness unsettles sociocultural expectations of health in young adulthood, unsettles work, education, and family formation, and unsettles how young adults experience their bodies. This chapter examines the strategies young adults employ to “figure out” life after a cancer diagnosis, asking the following questions: What strategies of actions do young adults employ in life after a cancer diagnosis? How are these strategies culturally informed? Finally, how do these strategies reinforce or resist unequal institutional arrangements?

Just as life after a cancer diagnosis is not conclusive and tidy, the strategies young adults employ are not conclusive and tidy. They are left to “figure out” life in the absence of institutions and protocols that meet their needs and the needs of their bodies. At the same time, they receive cultural messages that label them “survivors” and “thrivers” – labels that, regardless of whether young adults choose to take them up, shape the expectations young adults have for themselves. Prior literature details how individuals adapt to illness in – and as – a way of maintaining self-worth. Individuals are active in creating lives and themselves (Charmez 1995) as they mobilize resources to normalize the biographical disruption caused by illness based on “cultural circumstances and connotations” (i.e., the symbolic meaning of illness) (Bury 1991: 462). At the same time, adaptation is not an act of the individual. While agency is important, adaptation is

contingent on social and cultural context (Atkin, Stapley, and Easton 2010). This adaptation to illness is mediated by race, class, and gender, involves choice and constraint, and necessitates considerable material, physical, and emotional resources.

As young adults "figure out" life after a cancer diagnosis, they are bombarded by cultural messages defining "survivorship"<sup>10</sup> and detailing what life should look like after cancer's "conclusion." The dominant messages of this cancer culture frame cancer as a source of development and post-traumatic growth (Steinberg 2015; Ehrenreich 2001, 2009; Bell 2012). Such messages emphasize the importance of "positivity," going so far as to make connections between this emotional resilience and positive physical health outcomes (Youll and Meekosha 2011; McGrath 2004). As the terminology of "cancer survivor" has been critiqued for its failure to capture the enduring uncertainty associated with cancer, other terms have emerged, including the recent "cancer thriver"<sup>11</sup>. As a verb, "thrive" means to grow vigorously or to progress towards a goal despite conflict. In many ways, this semantic change reinforces the dominant ideals of cancer culture via the centrality of *development* and *growth*. Thrivership reinforces *ideas* of cancer as a "teachable moment" and an opportunity for "post-traumatic growth" (Bell 2012).

Critical interpretations of survivorship and mainstream discourses illuminate how cancer culture is embedded in, and shaped by, neoliberal logics<sup>12</sup> (Bell 2012; Youll and

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<sup>10</sup> I do not provide a genealogy of "cancer survivorship" in this chapter, as others have pursued that.

<sup>11</sup> I do not discuss the movement from "survivor" to "thrivers" in this dissertation. However, this term was prevalent in YA cancer organizations and referenced by interviewees embedded in those communities.

<sup>12</sup> As asserted by Bell (2012), "Prevailing frameworks and interventions rely on a set of assumptions about the nature of selfhood (and statehood) that have become thoroughly naturalized today. These assumptions presuppose the desirability of the autonomous, responsible subject/citizen obliged to make his or her life meaningful through acts of choice that maximize emotional, physical, and economic health."

Meekosha 2011). Bell (2012:596) argues that this movement extends neoliberalism from merely a political and economic rationale into “naturalized assumptions of selfhood<sup>13</sup>.” With this, cancer discourses emphasize autonomy and personal responsibility rather than dependency and maladjustment (Rose 1990:214). Discourses of cancer culture are not only descriptions of experiences of cancer but prescriptions of how individuals should conduct themselves (Bell 2012:596).

Regardless of the acceptance or rejection of the survivor or thriver identity, cancer culture serves as a powerful backdrop that informs strategies of action for young adults post-cancer diagnosis. Swidler (1986) argues that culture does not define the goals of action but provides "chunks of culture" used to construct "strategies of action." This toolkit contains habits, skills, symbols, stories, and worldviews (273). Publicly available meanings facilitate certain patterns of action, making them readily available while discouraging others (283). This emphasis on culture-work instead of identity-work is particularly appropriate as the role of culture in shaping action is more easily detected when lives are unsettled (Swidler 1986, 2001) and cancer serves as a significant change or transformation and, even in times of 'health,' young adulthood is a life-course stage associated with transition. Further, as I have shown in the preceding chapters, an off-time illness disrupts -- or unsettles -- the lives of young adults. When young adults are disrupted from personal and societal expectations by illness, culture is more visible as new strategies of action are "in tension with the previous medley of action and experience" (Swidler 2001:94). I aim to illustrate how responses to illness are embedded

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<sup>13</sup>Bell's assertion is similar to Foucault's theory of governmentality, where political rationales shape action through technologies of the self.

within inequitable systems that shape the response – and critiques – to existing social arrangements.

Overall, my goal in this chapter is to conceptualize life with cancer as *work*. Young adults *work* to reestablish identity and meaning in the context of the disruption caused by cancer. I characterize this labor as *resilience work*, constructed based on cultural expectations of growth, development, and elasticity in the face of hardship. Resilience work asks young adults to be positive and manage emotions to facilitate and reflect their own positive development. Importantly, resilience work is constructed with "pieces" of contemporary commonsense ideology that become salient in particular moments or for particular people as they attempt to re-settle their lives. I focus on three co-occurring forms of resilience work: bodily labor, family work, and support work. As this labor takes material, emotional, and physical resources, it is unevenly taken up across young adult respondents. Bodily labor is most prevalent in those who have completed active treatment, reflecting the cultural expectation that young adults take personal responsibility for their health to prevent recurrence. Women with children are more likely to engage in family work, reinforcing gendered cultural expectations that emphasize the performance of emotional carework and intensive mothering. While the desire to engage in support work is nearly universal, perhaps due to sampling techniques, the manifestation of support work varies by race and class. The commonality across these categories is that resilience work is arduous. This work requires emotional, physical, and material resources that are not free or infinite. This work is invisible; it does not pay wages or offer benefits like health insurance.

A note on language: I choose not to use the term "cancer survivor" in this chapter. While the terminology is commonplace in much of the cancer literature, it has been the subject of critique by researchers, cancer communities, and the narratives of my participants who do not experience cancer as an acute event that one "gets beyond." In response, the official definition of cancer survivorship has transformed from the tertiary phase of illness, or the third-period phase following diagnosis and treatment, to a stage *beginning* at diagnosis. While the genealogy of the term "cancer survivor" is a project of future inquiry, I favor the term "post cancer diagnosis" to capture both my participants' lived experience and the term's transitioning meaning.

### **Unsettled Lives**

This findings section begins with a discussion of age-specific uncertainty, a central theme in young adult lives post-cancer diagnosis, that yields support for the unsettledness of an off-time illness. I continue by illustrating the strategies of actions young adults employ post-cancer diagnosis and describe the institutional and cultural context from which they emerge. I find that the strategies of young adults are shaped by pieces of common sense narratives and ideologies.

### **Uncertainty**

In crafting this chapter, I struggled with how – and to what extent – to engage with the concept of uncertainty. On the one hand, the lives of my respondents were rife with uncertainty: Uncertainty if the cancer was present in their body, uncertainty as to what the next scan would show, uncertainty if they would watch their children graduate high school, make it to retirement or live long enough to see the sequel of their favorite movie. In many ways, *uncertainty* is central to the experience of cancer generally and the

experience of cancer in young adulthood. Prior scholarship shows that cancer is not experienced as an acute disease (Fosket 2000; Frank 2005; 2013; Kaiser 2008). Instead, individuals who have completed treatment find themselves *between* sickness and health, undergoing continued medical surveillance and medications, fearing recurrence, and remaining preoccupied with the possibility of disease and untimely death (McKenzie and Couch 2004; Little et al. 2002; Frank 2005, 2013). My findings confirm these patterns, with the vast majority of young adults experiencing health-related anxiety. This remained true for those diagnosed with "good cancer" with high survival rates and "easy" treatments, reflecting the good/bad cancer binary (Bell 2014).

What is unique about the theme of uncertainty for young adults is how uncertainty violates cultural expectations of young adulthood. Young adulthood is framed as a period of possibility with different choices for the future. As such, uncertainty is associated with a previously unrecognized awareness of vulnerability, fragility, and mortality that conflicts with the cultural expectations of young adulthood. For the vast majority of young adults, a cancer diagnosis challenged this normative, explanatory system by which they understood their biography, creating uncertainty about their remaining biological time (or how much time they had to live) and challenging the control they had over their lives.

As young adulthood is a transition period, young adults have not achieved long-term goals and expectations for their lives. This evokes a temporal awareness evident in the respective statements from Amira (30, white, colorectal) and Jasmine (38, Black, colorectal): "If I find myself upset, I get over it quickly because I don't want to waste any time being unhappy," and "I've been strapped with something this young...now I don't

have a ton of time. So, I gotta, you know, make the best of every opportunity and every situation.” This overarching uncertainty in time was framed as an age-specific experience, as seen in the excerpts by Monica (28, white, thyroid), “older people who have gone through cancer have done a lot of things that they wanted to do in life,” and Carlos (32, Latinx, colorectal), “you know, [older survivors], they have lived a full life, they had a great career or had a great house, you know, whatever it may be. Young survivors don't really have that opportunity.”

Since I'm so young, my whole life has gone by slowly, and I've been impatient to get to the next step. I don't remember any time in my life before my diagnosis thinking about getting old...But now I kind of feel like things are going by very fast. I'm looking back on things that I did, my past experiences and saying, *oh, I'm glad that I did that*, and I'm way more in tune with things that I wanna do in the future because I feel like time is going by fast and or my time won't be as much as others.

The awareness of biographical time, the feeling that young adults had yet to "live a full life," and the desire to not "waste" time was not dependent on prognosis, stage of disease, or those out of active treatment. For young adults, the disruption and discontinuity caused by cancer endured after the conclusion of active treatment and regardless of illness status, further reinforces the utility of understanding cancer in young adulthood as a unique experience with cascading impacts.

Uncertainty over biographical time does not just operate metaphorically based on abstract uncertainty or fear of eventual mortality but as a reaction to actual health status. Shannon (36, white, colorectal) describes planning her life in "three-month intervals" as



she navigates the uncertainty of her metastatic disease, which has a 5-year survival rate of less than twenty percent. “Until you've actually looked at the statistics for something you have, I don't think it's easy to explain to anyone what it feels like and what it means for not just parts of your life but all of your life.” She describes the difficulty of planning her personal and professional life around uncertainty.

My oncologist said to me, 'every three months, we're going to do a scan, and we're going to hold our breath,' and what affects me more is the world view of planning my life in three-month intervals... I know a lot of people will talk about scanxiety and being anxious before a scan, but for me, it's this sense of the unknown and this feeling of hesitation about *how much I plan?*... The hardest part should be thinking about what the scan really means, as it could be a much more severe prognosis. But for me, it's that I want to be able to keep doing the things I was supposed to be doing even if I didn't have cancer. It can be small things too. Like, my husband asked me a few weeks ago, ‘Should we plan a trip for the summer?’ And I'm like, I don't know. Like, yes, I'd like to go somewhere, but I don't know what the scan results are going to show. I don't know if I'm going to have surgery. I don't know if I am having surgery or when that surgery is going to be. There's just this complete inability to plan, even normal, simple things that you should be able to plan.

As Shannon describes the struggle to create timelines for her dissertation fieldwork and program completion, she states, “I don't know which intervals of time are actually going to be mine.”

In the proceeding section, I illustrate three forms of resilience work that young adults employed in the context of this uncertainty: bodily labor, family work, and support work. As culture is more evident when lives are unsettled (Swidler 2001), I briefly describe how each strategy of action is culturally informed. Finally, I argue that, in the context of a life stage associated with peak productivity, health, economic contribution, and caregiving (by caring children and aging parents or by contributing to social security via the taxation of wages), the pressure for young adults to conform to culturally appropriate strategies of action that young adults see as available to them.

### **Bodily Labor**

The first strategy of action was the engagement in bodily labor. I use the term bodily labor to describe strategies that center on the physical body, including engagement in protective health behaviors like alterations in diet and exercise, as well as techniques of self-surveillance, where young adults describe being hyper-aware of bodily functions or in a heightened state of alertness for any potential bodily abnormalities. Cancer organizations and healthcare clinicians encouraged bodily labor as a strategy of action by encouraging young adults to "take responsibility" for their health. The strategy of "bodily labor" reflects the underlying neoliberal logic embedded within cancer culture (Bell 2012), whereas the burden of detecting relapses and recurrences shift from the medical system to the individual young adult patient.

For young adults, bodily labor is motivated by the bodily experience of cancer and the violence enacted on the body during cancer treatment. At a life stage associated with health, this bodily labor is not about achieving the cultural ideal of fitness and health. Rather, bodily labor is a response to the experience of illness that cultivate

ongoing anxieties around health, mortality, and disability. Carlos (32, Latinx, colorectal) demonstrates the transformation of ideas associated with bodily labor:

I think about my health constantly, whereas before, I don't think I ever thought about it...now I realize that health is a perpetual state of how you are living.

Everything you do affects your health...I used to look at health as a very passive thing that would just always be there for me. Now I know that it's not. Health is something that you have to work to maintain.

Importantly, bodily labor as a strategy of action occurs within the context of increasing privatization of health services, dissolution of professional authority, and destruction of welfare provisions in which "the individual" is endowed with responsibility for their own wellbeing (see: Stacey 2013). As such, bodily labor is a form of emotion work that allows young adults to reassert control over their illness experience in the context of decreasing contact with the medical system while also ensuring that young adults comply with neoliberal ideals of individualism and personal responsibility. As asserted by Peterson (1996:48-49), "[neoliberalism] calls upon the individual to enter into a process of their own self-governance through processes of endless self-examination, self-care, self-improvement."

#### *Protective Health Behaviors*

Bodily labor included engagement in protective health behavior, through which young adults engaged in exercise, diet change, and other lifestyle activities to minimize the chance of a recurrence, secondary cancer or to slow disease progression. Such ideals are common in the context of cancer recovery, where an individual is encouraged to see their recovery as a project (Stacey 2013). Cancer survivors are susceptible to messages

that link lifestyle behavior and cancer prevention to diminish the possibility of disease recurrence (Bell 2010). Such protective actions often fell outside the standards of normative medical or treatment regimens. However, they were encouraged by mainstream oncology care to capitalize on cancer as an opportunity for positive lifestyle adjustments and as a catalyst for physical development (Bell 2012). Expressed lifestyle changes included using only “clean” personal care and beauty products, paying close attention to nutrition, cutting out processed food and red meat, and transitioning to a vegetarian or plant-based diet. For example, Julia (38, white, breast) describes her attempt to protect herself and her daughters from "chemical" exposure via home, health, and beauty products and eating a diet that restricts corn and soy. “We have really revolutionized our [personal care] products. I wear beauty counter makeup and shop to ensure that our products are chemical-free. I’m also wary about corn products, and I make sure that we don't eat any soy.” The emphasis on individual consumption reasserts neoliberal ideals of personal responsibility (Guthman 2011; Petersen 1996). Here, the burden is on Julia to protect her family via informed consumption rather than governmental regulation.

Shannon (36, white, colorectal), whose metastatic disease responded favorably to treatment, uses exercise as a protective health behavior to minimize the likelihood of recurrence. Shannon, who was “fairly active” before her cancer diagnosis, describes how her motivation for exercise changed because of the lived bodily experience of cancer:

The exercising part never necessarily took a priority for me as an adult. Other things, like work, would always come first. Post that first diagnosis and treatment, I really prioritize [exercise] more because there is research that says that exercise

is really effective in kind of keeping cancer at bay, and people who exercise more are less likely to have recurrences. So, I started just literally making that almost my first priority every day.

Shannon illustrates how the prioritization of exercise changed in the context of her illness experience, stating, "everything else has to fit around [exercise]." The motivations and incentives for engagement in bodily labor are not singular and change across one's moral career (Crossley 2006).

Mark (28, white, blood), describes how exercise takes on new meaning in light of his cancer diagnosis as a way to minimize the late effects of cancer treatment. "When I go to work out, I immediately think every time, *I should go work out because my heart doesn't work as well as other people my age because I have had radiation, so I really need to focus on my cardiovascular health more than I otherwise would.*" Mark continues by distinguishing between his motivations for bodily labor compared with other young adults:

That's not something you think about if you haven't gone through treatment.

[Others think], I should work out because, you know, it's healthier, I feel better or at least positive endorphins or because I've got a little bit of weight from last Christmas that I want to work off or whatever... but for me, it's because my heart is not as healthy and I don't want to have a heart attack.

Julia, Shannon, and Mark all demonstrate how young adults engage in protective health behaviors to minimize cancer risk, prevent recurrence, and minimize the late effects of treatment. Notably, engagement in such actions requires access to financial resources to buy healthy food, pay for a gym membership, and buy "clean" products that are often

more expensive and less accessible. The emphasis on bodily labor as a protective health strategy reflects the emphasis on physical development embedded in cancer culture. The individualized nature of this resilience places the responsibility for recurrence prevention in the hands of individuals rather than the medical system.

For Mariana (38, Native, colorectal), bodily labor involves incorporating various alternative medicines, including a marijuana-derived oil and herbal tea, as well as dietary changes. While her stage-three cancer was operable, she concluded treatment early due to dihydropyrimidine dehydrogenase deficiency (DPD), where the body lacks the enzyme to break down chemotherapy. In these cases, chemotherapy remains active in the body and continues to damage all rapidly dividing cells, causing severe or fatal reactions. “[My doctor] told me this numerous times [that] chemo is the backbone of this treatment for this cancer...so basically all they can do is watch me and monitor me: blood work every two months, CAT scan every three months.” She continues, “I don't want it back, you know? I mean, I am trying anything and everything I can get my hands on to where this thing won't come back... I tried the chemo that didn't work. And I was like, that's okay. I got backups, you know... I'm doing it all.”

### *Self-Surveillance*

Bodily labor also took the form of bodily awareness and self-surveillance. Here, young adults describe being hyper-aware of bodily functions and experience a heightened state of alertness for any potential bodily abnormalities (or abnormal bodily sensation) as a mechanism to detect any potential signs of cancer progression, recurrence, or potential adverse side effects. This bodily surveillance demonstrates ongoing bodily dys-appearance, or the non-normative awareness of the body that occurs in times of pain or

illness, in contrast to the body “moving to the side” of awareness in times of health (Leder 1990). The dys-appearance of the body was expressed by young adults receiving maintenance treatment, those in remission, and those who were considered "cancer free," thus demonstrating that the dys-appearance associated with cancer in young adulthood persists even after the conclusion of active treatment. The heightened awareness of the body violates cultural expectations of young adulthood, as bodies at peak health are taken for granted and therefore "absent" from awareness (Leder 1990).

Amanda’s (33, white, breast) self-surveillance demonstrates the persistence of bodily dys-appearance, as well as the in-betweenness of health and sickness (Frank 2005, 2013). Despite the conclusion of active treatment, Amanda remains hyperaware of her body, attributing any abnormal bodily sensation to a sign of a recurrence. She asserts, “I don’t *have to* think about [cancer] anymore, but in reality, it’s always there. If I feel a little icky, I don’t think, ‘oh, these are flu symptoms.’ I’m like, ‘Oh, I have cancer.’ Even though I had nothing, I didn’t have an ache. I didn’t have a pain.” In another example, "with every single cramp or pain [I think] “*what’s that? Oh, what’s this?*” And you know, just different changes in your body. Like you’re always gonna have that in the back of your mind. Like, “*Oh my God, I could have a recurrence, and I could be dead next year or something.*” Even young adults in complete remission for five years still expressed difficulty in "letting go of the fear" and "remaining confident" in their health status, engaging in similar self-surveillance techniques and protective health behaviors. However, not all young adults expressed fear associated with the chance of recurrence. Michael (33, white, testicular): "I don’t think I’m generally unhealthy because of the

cancer. I don't think it's going to show itself in other ways that I don't think that I'm like doomed to have a recurrence or that my health is going to be impacted.”

The importance of self-surveillance in the context of diminishing medical contact and personal responsibility for health was emphasized by Mark's (28, white, blood) oncologist, who told him “self-diagnosis” was more effective than traditional lab work or scans at detecting recurrence. Importantly, this “self-diagnosis” occurs as Mark's contact with the medical system, specifically his oncologist, occurs only annually. As such, Mark describes himself as "waiting for a symptom," which exacerbates his bodily dys-appearance. He explains a major consequence of this institutionally-exacerbated anxiety: "I know what to look for, I know the severity. But I am still always anxious... There's always a baseline level of anxiety around my health.” While it is outside the purview of this dissertation to assess the medical validity of “self-diagnosis” being “more effective than traditional lab work or scans at detecting recurrences” -- specifically in the context of high rates of misdiagnosis – Mark's narrative demonstrates how the bodily labor of self-surveillance, i.e., “self-diagnosis” is institutionally disseminated. This emphasis on personal responsibility shifts the burden of detecting relapses and recurrences from the medical system to the individual young adult patient. As such, bodily labor as a strategy of action reflects and reifies the neoliberal project of personal responsibility.

Bodily labor also emerged during participant observations, where it was emphasized as a strategy of action by young adult cancer support organizations. With this, young adult organizations support and disseminate cancer culture's underlying neoliberal ideologies through discourses associated with bodily labor. The program at a young-adult cancer-specific convention encouraged young adults to engage in meditation,



maintain a healthy diet via "eating for cancer," and "take control" of their health in the aftermath of diagnosis and treatment. This reflects the tendency for oncology clinicians to exploit cancer as an opportunity for active interventions that promote adherence to lifestyle behavioral guidelines (Blanchard, Courneya, and Stein 2008; Bell 2012). In a panel discussion sponsored by a sizeable cancer-specific health organization, young adults were encouraged to "own" their survivorship by taking responsibility for long-term, follow-up care (because, as explained by one speaker, "long-term follow-up care is often neglected" because "older doctors don't know what to talk about" or "there isn't enough time"). These panels served as knowledge-gathering spaces where young adults eagerly sought information to understand further their conditions, risks, and specific health statuses. This included being actively aware of the conditions for which they experienced an increased risk (including leukemia and heart disease) and being aware of the routine follow-up tests they would need in the years following the conclusion of treatment (for example, an echocardiogram and pulmonary functioning test after both 5 and 10 years). Young adults were also encouraged to "take responsibility" for their medical history by keeping all medical records in a note on their smartphone so they could be accessed at any time. This reinforces underlying power inequities by encouraging young adults to navigate age-specific limitations in care not by reshaping patient-provider relationships, expanding access to healthcare, or advocating for improved informed consent but rather by individualizing the responsibility of follow-up care. With this, the burden is placed on young adults to be active information-seekers and to "own" their thrivership. This burdens the individual patient and privileges those with healthcare

capital. With this, organizations emphasize individual self-care and psychological wellbeing.

Finally, the experience of Eric (34, Black, blood) demonstrates how continued medical contact and surveillance can help to *diminish* the anxiety related to one's health status. In the following example, Eric describes how continued contact every three months provides a sense of security.

Now that I'm post-transplant for six years, I should only go for yearly checkups. But since I'm going in there every three months, I have the confidence to know that if something were to ever return, it would be caught early. And that gives me some peace of mind somewhat. Just because, like, sure, I worry about relapse all the time, but I'm able to put it on the back burner, for the most part, knowing that I'll have checkups and bloodwork in three months or sooner. And if something is there, it will show up, and we'll take action immediately... There is still fear there, but it's not to the point where I'm *drowning* in it. I can live my life and make plans and prepare for the future, whatever that may look like. But I'm confident enough to know that I'll be able to make it through whatever comes if something were to come again. And that's only because of my frequent checkups with my doctors.

This example illustrates the role of institutions in alleviating or exacerbating the feelings of anxiety and fear that buttress bodily labor as a strategy of action for young adults.

### **Family Work**

The second strategy of action, the renewed focus on family, was expressed universally by women with young children, who made up roughly a quarter of the sample. This theme is characterized by engagement in emotional care work and

mothering responsibilities. Family work becomes a “tool” for young women based on gendered cultural expectations associated with nurturing, caregiving, and emotion work. Women are held accountable for family work in a way that men are not; thus, family work remains central to how women construct a gendered self (Erickson 2011). As such, family work is not experienced as a burden but a meaningful and symbolic expression of what it means to be a wife and mother and becomes central to identity (Erickson 2011; Hochschild 1979; Hochschild and Machung 2012).

For all mothers, the disruption caused by illness was often framed based on the impact on children and partners. In response, mothers described sustained *work* to maintain “normalcy” for their children despite physical and emotional pain and sustained emotional *work* on relationships with partners (which often included attending to a partner's emotional wellbeing). In the words of Gloria (32, Latinx, breast), a mother of two, "as a mom, you don't have the option to not get out of bed." The underlying sentiment of this statement is that mothers are not provided the space to take care of their emotional and physical wellbeing. Instead, women recognize that as mothers, they are accountable for the performance of this labor in ways that fathers are not.

Chloe (34, white, breast) describes herself as "always taking care of the kids and my husband first." With diagnosis and treatment, this was disrupted, "the focus was on me, and me getting better and help me and help me." She describes difficulty being "a normal mom" and treatment "really taking a toll on her kids." She recalls having difficulty getting down on the floor to play, being unable to take her children to places like parks and on play dates, and losing energy and her "happy moods." In the aftermath of this disruption, Chloe describes the importance of redirecting attention from herself to

her children and husband and returning to the roles she considers "normative." Family work is experienced as an expression of what it means to be a wife and mother (Erickson 2011). While Chloe continues to experience long-term side effects from treatment and lacks confidence in her health status, she firmly and purposefully places attention on being present with her family: "I try to just enjoy the time that I have with my family and try not to dwell on and think about the fact that five or ten years down the road I'll have to go through this again."

Melissa (31, white, breast), who has three young children and works within the home as a "stay-home mom," emphasizes the importance of maintaining her role as a primary caregiver for her children. She identifies with what is characterized as the "traditional mother" (Garey and Arendell 2001), who engages in full-time caregiving and domestic work and prioritizes, in her own words, "being there for her children" over working outside the home (Johnston and Swanson 2006). For Melissa, the intensive demands of treatment made her unable to perform the most taken-for-granted parenting activities central to her identity as a mother, such as cuddling a sick child.

When you're in treatment and immunocompromised, you have to be really careful not to get sick. As a mom, that's really difficult. If your kids are sick, you can't take care of them. You can't even hug and cuddle them. You've got to isolate and keep away from them. It really goes against all your [mothering] instincts.

In reflecting on a particularly salient moment, Melissa describes an occasion when her oldest son had a stomach bug and was "throwing up all over the place." She describes her husband, unfamiliar with care work, as "clueless" about how to clean up vomit. "He had no idea what to do, and I couldn't help him out. I ended up yelling instruction from across

the room, you know, *'get a paper towel and scrape up the vomit!'*" This incident is significant for Melissa, as she was forced to "stand there and watch." As she moves farther from the active treatment and regains her immunity, she describes the importance of "making up for lost time" with her children.

Chloe and Melissa describe how their family work is based on the pressure of intensive mothering, or a child-centered, emotionally engrossing, and labor-intensive endeavor where the mother takes responsibility for the needs of the child, with the child's needs taking precedence over those of the mother (Hays 1996, also see: Garey and Arendell 2002; Wall 2001). As the demands of cancer treatment conflicted with the gendered demands of intensive mothering, young women reasserted the importance of family work and intensive mothering. In the context of disruption, mothers remained committed to the middle-class ideal of intensive mothering, trying to minimize the impact of the disruption on children and partners.

Mothers most successful in maintaining parenting goals describe support outside their romantic dyad. For example, Amanda (33, white, breast) describes the role of community in realizing her desire to breastfeed her daughter until her first birthday. This desire was so strong that, following her mastectomy, she considered postponing treatment that would negatively impact her milk production. "A big part of me was like, I'm just gonna not do it. I'm going to nurse her. I'll worry about the hormone therapy later. We'll just get through this year, and I'll take my risks that it'll come back." Amanda ultimately decided to complete her recommended treatment protocol. While this decision was difficult, her access to donor milk was essential in signifying her community of support and alleviating her guilt of not breastfeeding. "There [are] all these people behind us, and

I just need to take care of me and make sure that I am there for [my daughter] when she has to go through this.”

I was worried that not breastfeeding would affect our bond, time, and closeness. That I wouldn't be able to give that something that only a mom can give. But it hasn't been that way... And there wasn't a moment where I was like, oh my gosh, we're running out of breast milk. I had breast milk coming out of my ears.

Amanda's initial response to postpone treatment until after she had achieved her breastfeeding goals reflects the ideology of intensive mothering, where the child's needs take precedent over the mother's needs (Hays 1996). For Amanda, access to donor breastmilk allowed her to maintain these parenting ideas – by providing her daughter breastmilk – without delaying treatment. With this, access to donor breastmilk allowed her to “take care of” herself while also asserting agency in the decision to breastfeed her child. In the context of disruption, mothers remain committed to the middle-class ideal of intensive mothering, trying to minimize the impact of the disruption on children and partners.

For young men unable to return to paid employment due to disability or lost work opportunities, family work became a way to compensate for limited options. For example, with his long-term professional goals upended, Michael (33, white, testicular) rearticulated his plan with an emphasis on family life rather than work life. Michael describes his long-term goals shifting from becoming a prominent litigator to starting a family, "I could potentially be a stay-at-home dad, which I would have never thought would happen." In another instance, Marcus (33, white, brain), whose treatment left him unable to work outside the home, describes "prioritizing" being a father for his two

school-age children. He states, "I want to be the father that I didn't have," demonstrating a desire to move away from traditional gendered divisions of labor that he experienced growing up. However, unlike the narrative of mothers, (potential) fathers did not frame family work as a "natural expression" of love for their children (See Erickson 2011; Wall and Arnold 2007).

Some young adults without family or long-term partners described the importance of maintaining contact and closeness with friends or what they deemed as their "chosen family." An unintended consequence of the emphasis on friendships was that close friends provided instrumental support for young adults without close family ties. Marriage undermines relations with the broader community, and the never-married are more likely to spend time with friends (Sarkisian 2006). Focus on family and friends is particularly important in neoliberal contexts where the state does not provide instrumental support for the long-term care of people with disability. This constant pressure to contain welfare spending in advanced capitalist societies means that informal, family-based care is socially necessary (Mowbray and Bryson 1984). As discussed previously, a cancer diagnosis in young adulthood can disrupt the formation of long-term partnerships and family formation. Reflecting on this disruption, some young adults describe emphasizing a chosen family or non-biological kinship bonds for mutual support and love (Gates 2017). For those young adults who found it difficult to form lasting adult romantic dyads, the strategy of focusing on chosen family provided an essential form of instrumental support often fulfilled by more traditional familial support networks.

The role of "chosen family" in providing instrumental support is demonstrated by the experiences of Jasmine (38, Black, colorectal) and Jennifer (39, white, sarcoma).

Both unpartnered middle-class women in their late thirties, Jasmine and Jennifer, described how close friends filled a gap in support and caregiving that would traditionally be filled by family (or, in the case of a more robust welfare state, the government). For Jasmine, a long-term friend, Susan, would accompany her to the doctor, schedule appointments, ask questions, and play the role of patient advocate. Jennifer (39, white, sarcoma), whose condition is terminal, describes making a “wheelchair pact” with a friend who also has a chronic illness. In the following excerpt, she describes their wheelchair pact and the motivation behind it:

She and I were talking very seriously last year about our health and how neither of us had stability in that regard. Neither of us has a family... our own nuclear family. So, we made [what we] called the 'wheelchair pact' where the first person who was in a wheelchair and needed help, the other would go to them, and we wouldn't ask questions. We wouldn't think about it twice. We'd just do what we had to do.

In the absence of a robust social safety net and without a family to provide extra-institutional support, young adults like Jasmine and Jennifer, without a partner or traditional family support, relied on close friends and "chosen family" to provide support.

### **Support Work**

Support activities took numerous forms and were often related to the needs of a specific cancer community, for example, young adult cancer, colorectal cancer, or BIPOC (Black Indigenous and People of Color) patients. The rise of condition-specific organizations, where individuals with the same illness share knowledge and experiences, is associated with the rise of embodied health movements and the trends in patient



empowerment (Brown and Zavestoski 2004; Brown et al. 2004). Breast cancer has been central in modeling what "good" survivorship looks like by emphasizing giving back and being a good-biomedical citizen (Klawiter 2008)

Involvement in support work was motivated by experiences of isolation, marginalization, and the lack of awareness and resources available for the target population. These motivations reflect in the distinct but analytically related and often cooccurring cultures of actions (Klawiter 2008): community-building, awareness and self-advocacy, and institutional reform. Support work became an outlet for young adults to fulfill the desire to help others associated with cancer survivorship (Little et al. 2000). Here, young adults mobilize to address the limitations of existing medical systems to meet the needs of a cancer population by providing community spaces of support (often unavailable in cancer centers) or by addressing institutional vulnerabilities experienced by young adults.

The most common form of support work was the engagement in age-specific community building. The prevalence of this theme may be due to sampling techniques and snowball sampling via these young adult networks. Age-specific community-building emphasizes overcoming isolation, building solidarity with other young adults, providing emotional support, and sharing knowledge. Young adults describe involvement in age-specific communities and the support they provide others as a form of service work. These communities included young adult-specific support groups, social media communities, and involvement with young adult cancer organizations. Michael (33, white, testicular) describes continued involvement with his age-specific support group as a mechanism to provide service to other group members: "I feel like I am more helpful to

them and that entire group...I feel like I'm there for them.” Monica (28, white, thyroid), describes her online community as a space where members remain “positive and lean on each other” in times of uncertainty. She describes: “I find a lot of peace in my groups on Facebook where people my age that share their experiences.” Geographically disbursed, young adults sought community in online groups and made connections via social media hashtags. Social media is associated with the creation of cancer support spaces online (Song et al. 2012).

### *Advocacy work*

Online communities served as consciousness raising spaces, helping young adults navigate personal choices and identify institutional barriers. As such, involvement in these communities led to larger YA activism. The emphasis of YA included awareness, personal health advocacy, and institutional reform. The young adults who engaged in advocacy work did so because they were "filling a gap" or meeting a need that was not represented in mainstream YA support work. Those young adults most likely to engage in this work did so because they were diagnosed with a lesser recognized cancer (for example, colorectal cancer) or because they were distressed by a lack of medical knowledge and protocols for young adults (for example, not being offered options to preserve fertility). Maria (26, Latinx, blood) describes "using her voice" to raise awareness of YA cancer and encourage young adults to engage in health self-advocacy to address high rates of delayed diagnosis. With this, she actively encourages young adults to seek medical advice for *any* abnormal bodily sensations: “my goal is just to get you to talk to your doctor about any symptom you're having, about any part of your body. If you have a weird mole, if you have headaches all the time, if you have this weird thing

growing out of your side, you need to talk to a doctor.” Danielle (27, white, colorectal) uses the language of obligation to describe her engagement in support work, “I feel like it's now part of my like responsibility to help spread that awareness whenever I can.”

Sophie serves as an ambassador for a large cancer organization and maintains a public profile where she provides support and guidance on personal health advocacy for other young adults. She feels pressure to "put this shiny gloss on" her illness experience, serving as a source of positivity for other young adults. "I'm trying to reach out to people and help them...Even on my worst day, [when] I'm at home crying over everything that happens, someone will message me, and I'm like, 'You're fine. The world's a great place. Don't worry about it.'" Maria and Sophie's emphasis on "positivity" reflects what McGrath (2004:25) characterizes as the "RA RA positive," or the "unwanted pressure from others to be positive" during illness. As such, we should understand the feelings of altruism associated with "giving back" as closely related to the culture of positivity that governs experience of illness (and cancer, specifically).

Carlos (32, Latinx, colorectal), became involved with advocacy due to dissatisfaction with the support group at his hospital and described turning to online communities to make contact with other young adults. "I needed to find other people like me, and that led me to a couple of online support groups. That's really when I started meeting people around my age." These online communities served as consciousness raising spaces, helping Carlos navigate personal choices and identify institutional barriers for young adults with colorectal cancer. "I knew that I wanted to be more involved. So it started off as just a kind of casual volunteer role and metamorphosized into something much bigger." At the time of the interview, Carlos worked as a patient navigator for

young adults with colorectal cancer, acting as a resource of age-specific information for other young adults with cancer: “I’m teaching people how to save their lives. I know how to ask the appropriate questions when to seek a second opinion, what to not be afraid of, and what to read and what not to read.” Despite the deep meaning Carlos gains from helping other young adults and colorectal patients, he describes the emotion work associated with support labor:

These conversations are not easy, and they bring up a lot of emotions for me...

They are very, very taxing emotionally on me, and I've just had to learn how to let it go... They're calling in for help and not calling in... [for me to tell] my story and to cry with them. They're looking for someone who has strength and can potentially talk them down off the ledge.

Sophie and Carlos describe the vast amount of emotional labor embedded with support work and the emotional management necessary to help other young adults through their illness experience.

### *Political Advocacy*

For young adults with dominant class capital, advocacy work occurs on the political stage, with young adults engaging with public policy through political lobbying and or the creation of Political Action Committees (PACs). Support labor at the political level was the least common among young adults as it required both the political capital to understand how to engage in political work and necessitated free time unavailable to all young adults. The goals of political advocacy were shaped by the larger context in which the advocacy occurred. For example, Jennifer (39, white, sarcoma) describes becoming involved in politics during the Affordable Care Act debate:

My friends and I formed a political action committee, and I was, for lack of a better word, I was the spokesperson for it. I told my story to senators and members of Congress in the lead-up to the Affordable Care Act. And what I told them was, "I have never been as frightened of my disease as I am of health insurance companies. I'm more frightened of them than I am of cancer. How fucked up is that? That's what I'm scared of." And I told that story over and over and over again to any member of Congress who would listen. And that's how we did it. We lobbied, and we organized political actions to help pass the bill.

Importantly, access to political advocacy is not about income or wealth but social capital. Social capital capitalizes on political engagement by enhancing the capacity for collective action (Lowndes et al. 2004). While Jennifer was "financially ruined," her social capital allowed her to join with friends to craft political engagement to fill the gaps in existing healthcare policy.

In more recent examples, the goals of the political advocacy were shaped by cancer organizations that facilitated political engagement and taught young adults how to "tell their story" in an effective way. Lindsay (37 white, gynecological) describes attending a two-day advocacy training offered by a survivorship organization:

You go down to DC, and they train you on how to tell your cancer story and what they're working on, like the financial aspects of cancer care, all these things that you would never know if you're not in it. But it's so eye-opening. And then the second day, you go on the hill and... you [see] your local senators and your congressmen. They have this simple thing...that is like "how to tell your cancer story" ...Basically, your stump speech or selling speech [that] has to be under two

minutes...And it goes, “Hi, I'm from \_\_\_\_\_. My life's changed and \_\_\_\_\_, but thankfully I was able to do this. I'm asking you to do this.” And then, “thank you for your support.” You just insert [yourself into] it. It's kind of like a mad lib.

Lindsay’s experience highlights how the rules and rituals of the political stage are something that must be learned - and rehearsed - before engaging in these interactions. She describes being trained "how to tell your cancer story" and taught "what [the organization] is working on ."The following day, Lindsay describes "sitting on the steps of the Senate with Cory Booker and Chuck Schumer talking about my cancer story." It is important to note that the individuals that often have access to these advocacy spaces are those with race and class privilege. The involvement of cancer organizations in facilitating institutional support meant that these organizations often shaped *what* needs – and *whose* needs – were emphasized including increased medical research on young adults, age-specific protocols, and addressing maladaptation. Importantly, like all support work, political advocacy was associated with vast emotional labor. This *work* echoed throughout the narratives of young adults:

If you're so involved in the cancer zone, then you're more aware when more people pass away. You have all these connections that are so much more painful instead of if you were just like this passerby or if you were like, *I finished treatment, later days, bye!*... But then, if you want to be more actively involved if you want to change the system, then you meet more people, and then you get hurt, and then it becomes so much more painful. And you're just like, if you change the system and you can help one more person, even if it's so small, and it's just like, Oh God, could I do it? Can I just walk away and not care? I don't think so.

## *Racial Justice*

For BIPOC respondents, support work focused on not only age-specific needs but also the needs of BIPOC communities, such as racial health disparities, inequality in access to health care, and structural racism. For these BIPOC young adults, support work filled a gap in mainstream young adult advocacy support work that took a “colorblind” lens. In one case, Joshua (33, Black, blood), who has been involved in the larger young adult-cancer community for over five years, describes how the needs of his community differ from the themes emphasized in the YA community and the failure of their tactics to reach a diverse audience. Joshua’s support work means encouraging Black people in his southern community to seek medical care when they experience abnormal symptoms:

In my [southern] community, Black people don’t go to the doctor. Luckily, my mom is a nurse, so I didn’t have that experience [because] I’m more trusting of medicine, so I went to the doctor when I started having symptoms... For me, advocacy means going to my friends and cousins, and others in my community and telling them to seek medical care when they think something is wrong.

Given his longstanding engagement with young adult advocacy and support, Joshua praises many young adult cancer support and advocacy spaces for their progress, for example, inviting BIPOC speakers and including more BIPOC people in conversations. However, his chosen advocacy reflects unique histories of institutionalized racism within medicine and a barrier to health care for BIPOC communities.

Jasmine (38, Black, colorectal) also expresses the desire to “serve her demographic,” suggesting an institutional and cultural disregard for Black women. Like Joshua, she critiques mainstream overly individualized approaches to cancer awareness,

stating, "I'm a Black female. I don't see that going back to a community of people who look and sound like me." Jasmine's emphasis on support work for Black women is motivated by racial disparities in colorectal cancer:

Colon cancer [has a] higher probability in African Americans, which is information that I don't think is truly out there... African American females specifically are a huge demographic of people who are affected; they either don't act on the symptoms they're having, [they] are misdiagnosed, or [they] don't have a voice.

Jasmine, whose diagnosis was delayed for over a year, uses her experience with the medical system to emphasize the intersections of race and gender to "help spread the good word and make my friends do it too" about the unique vulnerability of Black Women.

Finally, Mariana's (38, Native, colorectal) advocacy includes participation in a place-based environmental justice campaign investigating the role of environmental toxins in increasing rates of cancer in young adults. Mariana, an enrolled tribal member, grew up in Indian Country on tribal land. She became aware of the area's high cancer rates in young adults after she and her (young adult) sister were diagnosed with the same non-genetic cancer. "I was surprised by how many young adults up there have developed cancer within the last ten years." She describes becoming involved with a local environmental activist who is "kind of doing an Erin Brockovich on the area...[because] there have been more and more young adults developing cancer." She describes her and her sister "throwing [their] names in the ring" in her investigation of toxic exposure and rising cancer rates in young adults. In the following excerpt, she reflects on her history of toxic exposure and the impact it likely had on her health:



We have a lot of factories up there, and I have personally worked in three of them for a pretty good amount of time each. I'm sure I was exposed to all kinds of toxic stuff. My car's paint got eaten up just sitting in the parking lot. So, I can only imagine what it did to my body.

Mariana, whose case is likely terminal, emphasizes using her experience and her "testimony" to make a difference in the lives of others. "I'm willing to help in any way to prevent my nephews or my niece from getting this crap, you know?" Racism is a structural issue that impacts the distribution of environmental risk (Alvarez and Norton-Smith 2018). Mariana's emphasis on the role of environmental racism in shaping rates of cancer in young adulthood demonstrates the connection between macro-level structures and individual lives. At the same time, environmental racism becomes an individual problem that must be dealt with by mobilizing the individual.

### **Discussion**

This chapter explores young adults as they "figure out" life after a cancer diagnosis. From an individual-level reading of this data, this story may seem like one of resilience: Young adults are mindful of their health status, women with children focus on their families, and young adults across race, class, and gender engage in age-specific support as a way to support themselves and other young adults in different ways based on their unique positionality and perception of need. However, placing these strategies of action in a larger cultural context illuminates how ideology shapes responses to illness and the ways in which such responses require emotional, physical, and material resources.

Most importantly, this chapter illuminates the emotional labor associated with resilience work – work rendered invisible by commonsense ideologies. To be resilient to

off-time illness, to be a "survivor," to engage in bodily labor and take responsibility for your health, and to take it upon yourself to change the experience of other young adults with cancer require substantial and ongoing work. It requires emotional resources and is not infinite or free. The labor underpinning social expectations of "survivorship" is captured in the following statement made by Mitch (42, white, blood/sarcoma), who describes how the pressure to be a "successful survivor" after being diagnosed with a second primary cancer:

There's almost a societal expectation to go out and do something great...I need to go and do something great again, but I have also almost zero motivation to go and do so, which makes me feel even worse. Because not only am I not living up to me, I'm not living up to what society wants me to be, or what society wants to see, the successful survivor, and, oh, you've had it twice, you have to go into something twice as good. That's what I'm dealing with right now. There's an expectation that I need to go and be a superhero, and I just wanna sit at home. I just wanna relax. I've been through a show in the last couple of years. I'm tired.

Mitch's narrative illuminates the pressure to be a "superhero" and bounce back after his second cancer diagnosis. Mitch describes how embedded within this elasticity is an overarching pressure to "save the world" while lacking a "crusade" to go on. Here, Mitch demonstrates how his perceived failure to live up to expectations of survivorship serves as a source of emotional labor. This is perhaps what is most contradictory about the commonsense ideologies young adults draw upon; just as these strategies require emotional management and labor, similarly, failing to "live up to them" evokes emotional distress.

This chapter moves beyond literature that examines the “survivor” experience of young adults with cancer. This literature explores the impact of cancer on identity and self-concept (Darabos and Ford 2020; Langeveld and Arbuckle 2008; Song et al. 2012). I build on this literature, focusing not on the meanings young adults attach to their experience but rather how the strategies of action they use in life after a cancer diagnosis, with particular attention to how they reinforce cancer culture’s emphasis on growth, development, and individualized resilience. I find that pieces of contemporary commonsense ideology become more salient in particular moments or for particular people as they re-settle their lives.

This critical interpretation of cancer culture builds on the work of existing sociological research. Bell (2012) shows that cancer survivorship is associated with "post-traumatic growth" and is seen as an opportunity for physical and psychological development. Youll and Meekosha (2011) demonstrate that "positive thinking" in response to cancer minimizes stress and harm while reinforcing dominant neoliberal ideals of personal responsibility. Others have critiqued the characterization of cancer as enabling self-transformation and facilitating development (Bell 2012; Steinberg 2015). Dominant discourses frame cancer as a “unique opportunity to catalyze the patient’s physical and psychological development” (Bell 2012: 584).

I find that young adults also engage in bodily labor to limit, prevent, and identify any disease progression or recurrence, reflecting neoliberal ideals of personal responsibility. Bodily labor took on two interrelated forms: 1) protective health behaviors, in which young adults engaged in exercise, diet change, and other lifestyle activities to minimize the chance of a recurrence, secondary cancer or to slow the

progression of disease, and 2) self-surveillance, wherein young adults describe being hyper-aware of bodily functions and experience a heightened state of alertness for any potential bodily abnormalities (or abnormal bodily sensation) as a way to detect any potential signs of a cancer progression, recurrence, or potential negative side-effects. Bodily labor was encouraged as a strategy of action by oncology clinicians and young adult cancer organizations, which encouraged young adults to “take responsibility” for their health, placing the burden for recurrence detection and prevention and knowledge about long-term follow-up care on individual young adults rather than the medical institutions. This reflects the privatization of risk management, where the individual young adult manages the risk of cancer progression or recurrence through individual (lifestyle) choices, alleviating the burden placed on medical institutions.

Bodily labor as a strategy of action supports and challenges prior research. They support prior literature which emphasizes the underlying neoliberal logic embedded within discourses on cancer survivorship. For example, Bell (2012) shows how oncological discourses on cancer survivorship reflect the neoliberal logic of privatized risk management, where the individual is expected to take responsibility for managing the risk of cancer recurrence to alleviate the financial burden on the healthcare system. My findings challenge previous research that argues cancer survivors engage in high-risk behaviors (Cox et al. 2005). Instead, I find that young adults engage in protective health behavior to reassert control over health status and minimize the risk of relapse or recurrence, reflecting prior findings of Frank (2003) and Bell (2010).

I find that young women with heterosexual partners and young children emphasize family work. Family work describes the emphasis on caregiving and nurturing

associated with normative cultural expectations of femininity. Here, young adults described shifting attention from themselves, the receiver of caregiving during treatment, back to their children and husbands. Young women engage in family work, committed to hewing to the modern ideals of middle/upper-class intensive mothering, trying their best not to let the disruption of illness disrupt, even as it does. Young women demonstrate how "pieces" of contemporary commonsense ideology become more salient in particular moments for particular people as they re-settle their lives. For young women, gendered expectations of care work and ideologies of intensive mothering are reflected in the strategies of action young women employ.

Family work as a strategy of action for young adults with cancer extends prior research. This literature builds on work examining how gender shapes illness experiences (Wedgwood et al. 2020; Charmaz 1994; Parton, Ussher, and Perz 2016; Parton, Katz, Ussher 2019; Pound 1998) by showing how gender shapes strategies of action employed in response to the disruption caused by illness. Others have shown how women with children often emphasize the impact of illness on their children rather than themselves (Parton et al. 2017) and how women unable to fulfil expectations of nurturing and caregiving risk having their illness minimized (Montali et al. 2011). This extends this inquiry, showing that young adults with children attempt to repair this disruption by engaging in family work as a strategy of action. Ammons and Kelly (2008) note that literature on family work has yet to examine the experiences of the young adult cohort and life course literature has failed to examine work-family transition to adulthood.

I find that young adults engage in support work as a strategy of action, which encompasses involvement in peer-to-peer social support and advocacy work related to the

needs of a specific cancer community. Most support work emphasized age rather than condition, focusing on young adults with cancer. Involvement in support work was motivated by experiences of isolation, marginalization, and the lack of awareness and resources available for the target populations; young adults would *mobilize* to address the limitations of existing medical institutions to meet the needs of a cancer population. Support work focused on three distinct but analytically related and co-occurring cultures of action (Klawiter 2008, 2004): community-building, awareness and self-advocacy, and institutional reform.

The prevalence of support work places the burden for the emotional, physical, and social wellbeing of young adults with cancer on the shoulders of their peers. A dearth of institutionally embedded support programs means that young adults feel compelled to act as "ambassadors" for other young adults -- answering questions, providing access to resources, and raising the visibility of cancer in young adult bodies. Even when condition-specific organizations exist, these entities rely on young adults to "tell their cancer story" to facilitate fundraising and institutional reform, demonstrating the overreliance on informal care work in advanced capitalist societies (Mowbray and Bryson 1984). For example, the director of a young-adult cancer organization described the benefit of mobilizing the illness experiences in an interview, describing "stories that come from the patients themselves" as "the best and most effective promotional tactics."

Previous research describes the tendency for cancer survivors to engage in altruistic activities and service work that continues after the conclusion of active treatment (Little 2000; Frank 2003). Frank (2003:251) explores the role of service work in the craftwork of survivorship, as involvement in the world of illness is not self-evident. Frank describes

suffering as "the call to and preparation for works for further service," drawing on Schweitzer's (1990) assertion that serious illness awakens a responsibility beyond normative awareness. On one level, my interviewees exhibit what Frank (2003) terms "extensive responsibility" in their desire to make a difference. At the same time, young adults often do not have the privilege of "limited liability" in the aftermath of illness, as the social and physical disruption caused by cancer extends beyond the illness period. As this 'service work' results from the limitations of institutions, motivations should move beyond seeing service as an *individualized responsibility* but rather a sense of group responsibility due to the collective failings of institutions to support the needs of young adults with cancer.

My findings detailing engagement in age-specific individual and collective support connect with previous literature describing the emergence of – and involvement in -- condition-specific organizations. This literature emphasizes the specificity of illness experience as it pertains to a specific illness or disease. The experience of young adults with cancer and their involvement in *age-specific* organizations demonstrate how the life course stage surpasses cancer type as a uniting identity. I find that young adults mobilize resources and engage in age-specific organizations to address the limitations of medical institutions to meet the needs of young adults. Involvement in cohort-specific support groups does provide young adults space for individual and collective support. The burden of this labor falls on the young adult cancer patient and survivor rather than health care institutions and systems. Placing this burden on young adults means that young adults employ emotional management and labor.

Finally, in addressing racial differences in approaches to support work, I illuminate how mainstream cancer advocacy perpetuates the needs and perspectives of those with race and class privilege. This builds on the work of others (Ernst 2011) that show the limitations of colorblindness, particularly within the context of racialized institutions, like medicine or welfare. The actions of BIPOC young adults in targeting the needs of BIPOC communities should be understood as an anti-racist racial project (Omi and Winant 2014), as it attempts to “reorganize and redistribute” resources along particular racial lines. Future research should consider the impact of the life course stage in response to health inequalities. Responses to racism change over the life course due to different levels of social power (Vasquez and Norton-Smith 2017). Therefore, the responses of BIPOC young adults with cancer may differ from others at other life stages. With the emergence of age-specific cancer support, future research should examine young-adult-specific spaces to determine if they can overcome the limitations of other condition-specific cancer organizations.



## CHAPTER VI

### CONCLUSION

As I approach the conclusion of this project, I am overwhelmed by grief. Perhaps this seems like a strange feeling to be associated with a dissertation, as completion of this academic milestone should be a source of celebration. For me, this is not the case. I am acutely aware that a few – and perhaps several – of my respondents have not lived long enough to see this project come to fruition. During one of my first interviews in 2018, Carlos described survivor’s guilt as a symptom of institutional failure: the failure to capture the entirety of a young adult patient, the failure to consider the long and late effects of cancer treatment, and the failure to address mental health. He described the labor of immersing oneself in the world of young adult cancer and the labor associated with watching people you know and care about die. He recalled watching “vibrant” young adults who had “the rest of their lives to live cut very, very short” by cancer. In writing this dissertation, I have been completely immersed in the world of young adult cancer while simultaneously detached from this reality of death. I have had the luxury to engage with a young adult who is temporally suspended – forever captured in an interview transcript. In this moment, their illness has not progressed or returned. They continue to play with their dogs, kiss their children goodnight, see their doctors, and engage with the enduring uncertainty of illness. As I complete this project, I feel the weight of these vibrant lives; a responsibility to share their stories while protecting them from the reality outside these pages.

In the preceding chapters, I explored young adults' lived experiences of cancer. I sought to answer the following research questions: How did young adults experience self-diagnosis? How did they experience professional diagnosis? How did a cancer diagnosis impact their lives, from educational and occupational trajectories to relationships, intimacy, and family formations? How did social institutions mitigate or exacerbate the impacts of off-time illness? What responses did young adults employ in life after a cancer diagnosis? How were these responses culturally informed? The dissertation examines illness experiences as culturally and institutionally shaped and *age-specific*. This dissertation's primary contribution is examining a previously unexamined population, young adults with cancer. The findings contribute to sociological literature in medical sociology and the sociology of health and illness, demonstrating how age shapes experiences of illness in formal and informal ways, how the timing of illness during young adulthood influences the experience of disruption, and how social actors assert agency in the context of cultural and institutional constraints. Above all, this dissertation emphasizes the importance of age as an axis that structures experiences and social relations.

## **Contributions**

### *Emphasis on Young Adults with Cancer*

The primary contribution of this dissertation is the sociological examination of an understudied population: young adults with cancer. Biomedical advancements in the last 40 years have transformed cancers once fatal into chronic conditions. The benefit of such advancement has been uneven with young adult survival rates being significantly outpaced by increased survival rates in childhood and older adulthood. As such, young

adults with cancer are characterized as the most underserved cancer population, prompting the growth of research on this population in medicine, nursing, oncology, and social work. Sociological analysis of experiences of cancer in young adulthood, as well as the activities and growth of age-based organizations, provide an opportunity to place individual illness experiences in the context of social structure.

### *Emphasis on Age*

A central goal of this dissertation is to emphasize age as an axis that shapes individual experiences and social relations. Expectations attached to life stages are formalized through governmental policies that attach specific responsibilities, rights, and benefits to people at specific *ages* within the life course. Age should not be understood as an individual attribute or chronological fact (Laz 1986). Instead, age reflects – and shapes -- institutions and normative discourses based on cultural expectations about the life course. This conception of age is like that offered recently by Barrett and Michael (2022:185), who conceptualize age as an institution or “a structure of social relations scaffolded by ideologies about age and aging, grounded in practices to sustain them, and enforced by coercive social norms.”

For young adults with cancer, age shapes illness experiences in both formal and informal ways. Age is socially constructed and serves as a marker for *when* events should occur along the life course. Age provides a prescription of how individuals move through time, influencing their understanding of themselves and the social world (Hockey and James 2003). Notably, cultural expectations of *age*<sup>14</sup> shape social support systems, policies, and practices. These cultural expectations are also placed on young adult bodies,

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<sup>14</sup> These cultural expectations of age could themselves be considered “common sense” ideologies.

shaping expectations and interpretations of sensations. It is these cultural discourses and institutional practices that shape the experience of illness. Emphasis on age provides the opportunity to examine how young adults view their age as central to their understanding of their bodies, interactions with the medical system, and experiences as patients, thus setting the stage for the creation of age-specific extra-institutional organizations. For example, in chapter two, I demonstrate how age-based expectations of health in young adulthood framed self and professional symptom interpretation, yielding insight into how life course stage shapes young adult understanding of their bodies and how health care professionals perceive their bodies. I offer the term 'age-related blind spots,' where young adults, clinicians, and medical systems are slow to recognize ill health in some young adult bodies, as a conceptual tool to capture how life-course stage impacts diagnosis.

For young adults, age serves as an important aspect of identity. As Twigg (2012:1032) asserts, “age is surely one of the key or ‘master’ identities, along with gender, class, ‘race’ and other contenders.” The salience of age as an identity is evident in young adult rejection of a generalized cancer identity, often associated with older adults, in favor of a young adult specific biosocial identity. With this, young adults challenge this conception of cancer as a disease of old age by producing new collective identities with other young adults.

### *Biographical Disruption in Young Adulthood*

The second goal of this dissertation is to illuminate how the timing of biographical disruption during young adulthood creates unique and cascading impacts. The biographical disruption framework understands illness as a "major kind of disruptive experience" that disrupts daily life, expectations, and plans for the future, necessitating a

fundamental rethinking of biography and self-concept (Bury 1991; 982:169). Despite the vast application of the biographical disruption framework, central critiques point to its failure to acknowledge how social structure, timing, and context shape experiences of *illness*. The life course perspective asserts the importance of timing, emphasizing how the consequences of life course events and transitions vary based on when they occur in an individual's life (Elder 1998; Elder et al. 2003). Social norms and expectations dictate the appropriate "timing" of events and transitions along the life course, classifying them as "off-time" or "on-time" (Settersten 2003). As norms and expectations associate ill health with older adulthood (Gullette 2017), the timing of a cancer diagnosis in young adulthood disrupts cultural expectations. Focusing on individuals at one life course stage, young adulthood, I show how life course stage and the (off)timing of illness shape the experience of disruption.

Young adulthood is a period of transition and change, where individuals achieve the traditional markers of adulthood: completing education, entering the labor force, financial independence, marriage, and becoming a parent. The life course principle of lifelong development holds that experiences with cancer in young adulthood shape subsequent life stages as life experiences reverberate across the life course. In chapter three, I find that the (off)timing of illness during the transitional period of young adulthood has unique consequences with potentially long-term and cascading effects. I show how a cancer diagnosis disrupts the everyday lives, plans, and expectations of young adults in the key sites of education and occupation and relationship, intimacy, and family formation. Young adults shared disruption in these sites despite variations in diagnosis, treatment, and diverse positionality in the trajectory to adulthood. At the

critical juncture of the young adult life stage, I argue that these disruptions must be understood in terms of their potential long-term and cascading effects. I also find that the off-timeness of cancer in young adulthood challenges culturally-informed pathways to adulthood by disrupting the achievement of "traditional" markers of adulthood. I also illuminate the role of institutions in mitigating or exacerbating the disruption of cancer during young adulthood.

### *Structural Factors Shaping Illness Experience*

This dissertation draws attention to how structure and culture shape illness experiences. Grounding the research in the US context, which, compared to other advanced democracies, has a comparatively weak welfare state and health care that is not guaranteed, demonstrates how institutions exacerbate the disruption of illness. For example, Grinyer's (2009) analysis of life after cancer in adolescents and young adults (diagnosed between the ages of 14 and 26) in the United Kingdom fails to acknowledge the role of the National Health Service in shaping the experience of survivorship. Unlike the findings of this dissertation, the participants in Grinyer's (2009) study did not describe difficulty accessing treatment, fear of a loss of health insurance, or the high cost of care due to un- or under-insurance. While participants in the UK did describe long-term financial consequences of cancer, they were attributed to side effects, comorbidities, and disabilities, rather than financial toxicity, which, as a consequence of the *cost* of access to healthcare, pattern future employment, relationships, and family-formations. By examining the experience of illness in the context of employer based-healthcare and less-robust social safety nets, this study illuminates how structural conditions shape illness

experience and how young adults without guaranteed access to healthcare mobilize recourses to address gaps in institutional support.

An emphasis on structural conditions allows for a more critical reading of often overly individualistic responses to illness. For example, the biographical disruption framework describes how illness disrupts everyday life and forces individuals to reevaluate future expectations (Bury 1982). While important, such perspectives are often overly individualistic and fail to acknowledge how experiences of – and responses to – illness are socially constructed. I build on this literature to illuminate how cultural and institutional forces shape illness experiences. A central goal in this project is to further interrogate narratives that frame illness, and cancer specifically, as facilitating personal development and growth. Acting on such 'opportunities' requires engineering, support, or, at the very least, access to consistent and affordable healthcare.

### *Rethinking Resilience*

This project illuminates how vulnerability and resilience are socially constructed for young adults with cancer. For example, in chapter three I show how young adult resilience to employment disruptions was mitigated by robust workplace benefits, including health insurance, access to short and long-term disability, and workplace flexibility. In the context of disruption and institutional failure, young adults assert agency in ways to fill the gaps left by institutions. The natal family was central to the engineering that facilitated young adult resilience to an off-time illness for those otherwise outside of most age-based supports and lacking resources of their own. Upper and middle-class families provided young adults with direct financial support, while working-class families relied on community fundraisers to support young adults. While

essential, this renewed dependence on parents negatively impacted the self-concept of young adults as it challenged cultural expectations of independence.

Finally, finding themselves outside of existing support systems, young adults labor to facilitate their own resilience through various form of resilience work. For example, I show how young adults engage in peer-to-peer support and advocacy work related to the needs of a specific cancer community. This support work involved vast emotional labor and often reflected the needs of those with race and class privilege. With this, I demonstrate how inequalities are exacerbated as young adults from different racial backgrounds navigating racialized organizations that are buttressed by cultural understandings about what, and who should be at the forefront of advocacy. BIPOC respondents engage in support work that centers on the needs of their communities, working to fill a gap in mainstream young adult advocacy support work.

### **Limitations and Future Research**

A fundamental limitation includes the small sample size and variation among cancer types, stage at diagnosis, geographic locations, and the broad age range of young adults. Limitations also include variations around race, gender, and social class. Although I conducted interviews until I reached theoretical saturation and no new themes emerged, the sample of 40 young adults is not large enough to allow for generalizability. My sample also includes variations in geographic location across states with differing state policies and Medicaid eligibility, differing demographics, and treatment at various hospitals and cancer centers. A final limitation of my research is the vast variation in the bodies of young adult respondents. Even those with the same cancer type and stage will



not experience illness similarly. There are far too many variations in the corporeal reality of cancer that I cannot account for in this research.

The limitations of this research provide exciting opportunities for future inquiry. Future research should examine, more specifically, cancer experiences in young adulthood with specific parameters around race, gender, and social class. Future research should also examine young adults' experiences in one (or across) specific geographic contexts, among a larger sample, specific cancer type and time from diagnosis, across more demographic categories, and based on private vs. public insurance coverage. In the interrogation of large samples, it would be beneficial to employ a mixed-methods approach to keep the nuance provided by in-depth interviews and participant observations. A natural progression of this work would be to examine the experiences of young adults as time increases after initial diagnosis: 10-20 years after diagnosis, 20-30 years after diagnosis, etcetera. More research is needed to understand how the medical system uses age in formal and informal ways. How have age-based ideologies been codified into social and medical institutions to shape the experiences of young adults? What types of professional development or training might aid primary care providers, oncologists, clinicians, and others working in the medical field in support of young adults with cancer? Finally, future research should examine how age impacts individual experiences and social relations. How might other age-based ideologies perpetuate inequitable social and material environments?

### **Recommendations**

Recommendations based on my research findings include healthcare reform, an emphasis on an expanded conception of informed medical consent, and reconceptualizing cancer.

These recommendations may help support the survival and flourishing of young adults diagnosed with cancer.

### *Healthcare Reform*

The first recommendation of this dissertation is to expand access to public health insurance and lower individual out-of-pocket expenses. In the context of the increasing precariousness of young adulthood, the current employer-based healthcare system creates specific age-related blind spots in coverage for young adults as a demographic.

Compared to children or older adults, the young adult demographic is more likely to be uninsured or have minimal health insurance (Smith and Medalia 2013). Those young adults with low- or moderate-income households are most at risk. Lack of insurance has significant health implications. For example, Collins et al. (2012) found that 60% of uninsured surveyed young adults said they did not get needed health care because of cost. Such delays in help-seeking are particularly troublesome in cancer cases as many cancers spread rapidly, and the stage at diagnosis impacts treatment cost, intensity, duration, and 5-year survival rates.

Recent healthcare reforms have yet to go far enough to extend protection for young adults. Patterns of un and underinsurance remains even after changes in the Affordable Care Act extended coverage for some young adults, allowing them to stay on their parent's insurance until age 26 under the Dependent Coverage Provision (DCP). Despite this expansion, research shows that almost 40% of young adults ages 19-29 were without health insurance for all or part of a year (Collin et al. 2011). Many young adults are unaware of this expansion or pre-existing insurance options (Warner et al. 2014), and only some have access to parental health insurance. In addition, the coverage provided by

the DCP has been uneven, with Black and Latinx patients less likely to have private insurance before and after the Affordable Care Act-Dependent Coverage Provision, compared with white patients (Alvarez et al. 2018). Research demonstrates that the ACA-DCP improved healthcare coverage for those young adults that traditionally have access to resources and healthcare, reinforcing existing patterns of inequality and that insurance does not directly translate to increased access due to high out-of-pocket costs (Kirchhoff et al. 2012). Therefore, it is central to focus on expanding access for publicly insured groups and decreasing out-of-pocket expenses. While the ACA-DCE did expand coverage for a subset of the young adult population with race and class privilege, it reifies existing racial and socioeconomic disparities for those that already experience disparate survival outcomes (Alvarez et al. 2018).

The current private and public health insurance system reduces young adults' resiliency following disruptions to work and employment activities. Employment disruptions can result in health care loss for those with private health insurance. After the conclusion of active treatment, young adults have less flexibility in pursuing professional opportunities, as maintaining healthcare coverage is a central concern. Previous research speculates that employer-based health insurance results in job lock, little choice of health plans, and limited portability. Such patterns are exacerbated for illnesses like cancer that require ongoing treatment and long-term follow-up care. While Medicaid expansion increased access to public health care for low-income young adults, income restrictions mean young adults must remain asset-poor to continue receiving benefits, thus limiting their return to work.

Healthcare reform should include the development and implementation of universally accessible long-term follow-up care to meet the unique needs of young adults as they age. The best way to ensure young adults receive long-term follow-up care is to implement a universal public healthcare system where access to care is separate from formal employment. Ghaderi et al. (2013) find that after five years, young adults experience an increased risk of severe late effects, morbidities, chronic illnesses, and disabilities, resulting in diminished working capacity and prolonging the financial impact of cancer. For young adults with cancer, the risk of permanent disability increases as access to healthcare decreases (Ghaderi et al. 2013). Universally accessible healthcare is necessary for early detection and intervention to reduce the adverse health effects associated with cancer and cancer treatment. As the incidents and prevalence of cancer continue to grow among young adults, the collective and individual physical, emotional, social, and economic burden associated with the long-term consequences can be mediated with universal healthcare and accessible, long-term follow-up care.

#### *An Expanded Conception of Informed Consent*

The second recommendation is that healthcare professionals, including physicians, clinicians, and social workers, ensure an expanded conception of informed consent in all patient-provider interactions. This expanded conception of informed consent includes consent for a given medical procedure(s), transparency around possible side effects of treatments, access to treatment options themselves, and information about long-term follow-up care. While important in all contexts, informed medical consent is essential for young adults based on high rates of late-stage misdiagnosis and short-term and long-term side effects of cancer treatment. In the context of an off-time illness,

informed consent may look different in young adulthood than in other life states. Young adults have less social power than older adults, and healthcare capital likely increases with age, as does familiarity with medical institutions. Informed consent must encompass the doctor-patient relationships at every stage of illness, from diagnosis to long-term follow-up care.

An expanded conception of informed consent will address unequal access to fertility preservation and fertility-based information. While I am not the first to discuss the importance of informed consent in the context of young adults with cancer, medical literature often emphasizes physician disclosure of potential treatment-induced infertility and access to options for fertility preservation. While I support such initiatives, especially as women are more likely to experience treatment-induced infertility and less likely to be provided with options for fertility preservation, limiting the scope of informed consent to focus only on *fertility* fails to acknowledge the myriad of ways sexual and reproductive health may be impacted by cancer treatments, for example, side-effects on sexual pleasure and treatment-induced menopause. Further, the emphasis on *fertility* prioritizes women's reproductive labor, reflects (and reinforces) the massive growth of the reproductive bioeconomy, and fails to acknowledge that such fertility chains are highly dependent on the appropriation and exploitation of women's unpaid and paid reproductive labor (See: Vertommen et al. 2021).

An expanded conception of informed consent will also ensure that all young adult patients fully understand the potential long-term side and late effects of treatments and treatment options before starting treatment and are given precise long-term follow-up plans. While there have been calls to create young adult-specific "checklists" for

providers to cover with young adults, my finding demonstrates that protocols alone do not guarantee agency. As such, expanded informed consent requires moving away from evidence based medicine that fails to take account of the individual.

### *Reconceptualizing Cancer*

My final recommendation is to reconceptualize cancer as a disease that impacts all ages and stages of the life course. As I have shown here, the cultural construction of cancer as a disease of old age shapes the understanding of risk by both individuals and clinicians. The ideology underpinning this cultural construction, the association with old age with decline, has also been used to justify the irrationality of universal health care, as young bodies do not experience catastrophic illness. As such, reconceptualizing cancer will further support policies and practices that offer support to young adult bodies.

The case of colorectal cancer demonstrates the importance of reconceptualizing cancer, which, as I have shown, is conceptualized as a disease of older adults. While it is true that the majority of cancer cases occur after the age of 40, the incidence is increasing in young adults. Based on current trends, colon cancer is projected to increase by 90% and rectal cancer by 124% in those under 35 (Underferth 2020). As reflected by my sample, over 60% of young adult cases are diagnosed at either stage III or IV. I remind the reader that, if caught early, colorectal cancer is curable, while stage IV has a five-year survival rate of 20%. In recent years, the recommended age to begin screening for colorectal cancer has been lowered from 60 to 45. While this marks a significant move, it would not capture the experiences of colorectal cancer found in these pages. Further, as the young adults in my sample experienced prolonged IBS symptoms, they should have had access to a colonoscopy based on the prior guidelines. It is not enough to lower

screening guidelines, especially if those who exhibit symptoms experience barriers to diagnostic testing.

### **Final Thoughts**

This dissertation began after my family navigated the disruption of an off-time illness. Throughout our experience, I was struck by the inability of existing institutions to accommodate illness in young adults. To be a young body with cancer was to violate individual expectations, medical expectations, and the expectations of existing institutionally-embedded support. From the beginning of this project, I have struggled with the story I wanted to tell. On the one hand, the story of young adults with cancer is one of biomedical triumph: advancements in medical technology in the last forty years have turned cancer from a terminal condition to one that is chronic and sometimes curable. Many of the young adults in my sample, including my partner, would have faced different outcomes five decades ago. These interventions come at an emotional, physical, social, and financial cost—costs that are exacerbated by institutional support and practices. At the same time, young adults demonstrate resilience in their commitment to their families, responsibility for their health, and obligation to improve the experiences of other young adults with cancer. Young adults find ways to be resilient when institutions fail them. It is my final hope that this dissertation demonstrates the limitations of a system that places the burden of resilience on the individual.

## APPENDIX A

### SAMPLE DEMOGRAPHIC CHARACTERISTICS

**Table 1.** Young Adult Participants Demographic Characteristics

Name	Gender	Age	Race	Cancer Type	Class	Partnered	Parent
Alexis	female	38	white	colorectal	working	partnered	no
Amanda	female	33	white	breast	middle	partnered	yes
Amber	female	33	white	skin	middle	partnered	yes
Amira	female	30	white	colorectal	working	partnered	no
Brittany	female	35	white	sarcoma	middle	single	no
Carlos	male	34	Latinx	colorectal	working	partnered	no
Chloe	female	34	white	breast	working	partnered	yes
Christopher	male	21	white	colorectal	middle	single	no
Danielle	female	27	white	colorectal	middle	single	no
Donella	female	41	white	blood	middle	partnered	yes
Eric	male	34	Black	blood	middle	single	no
Gloria	female	32	Latinx	breast	middle	partnered	yes
Heather	female	31	white	colorectal	working	partnered	no
Hector	male	19	Latinx	blood	working	Single	no
Isabelle	female	26	Latinx	blood	middle	single	no
Jade	female	29	black	blood	middle	partnered	no
Jasmine	female	38	Black	colorectal	middle	single	no
Jennifer	female	39	white	sarcoma	middle	single	no
Jeremy	male	36	white	blood	middle	partnered	yes
Joshua	male	33	Black	blood	middle	single	no
Julia	female	38	white	breast	middle	partnered	yes
Kimberly	female	26	white	colorectal	middle	single	no
Lindsay	female	37	white	gynecological	middle	single	no
Marcus	male	33	white	brain	Working	partnered	yes
Maria	female	26	Latinx	blood	middle	single	no
Mariana	female	38	native	colorectal	working	partnered	no
Marin	male	28	Latinx/Asian	blood	working	single	no
Mark	male	28	white	blood	middle	single	no
Melissa	female	31	white	breast	working	partnered	yes
Michael	male	33	white	testicular	middle	partnered	no
Mitch	male	42	white	blood/Sarcoma	middle	partnered	yes
Monica	female	28	white	thyroid	middle	partnered	no



Nicole	female	28	South Asian	blood	middle	single	no
Paul	male	33	white	blood	working	single	no
Rebecca	female	34	white	breast	middle	single	no
Samuel	male	35	Latinx	blood	middle	single	no
Shannon	female	36	white	colorectal	middle	partnered	no
Sydney	female	28	white	blood	working	single	no
Tracy	female	39	white	gynecological	middle	partnered	yes
Wendy	female	24	white	blood	working	single	no

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