

## Chapter 11

### Adoption After Cancer: Adoption Agency Attitudes and Perspectives on the Potential to Parent Post-Cancer

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#### Introduction

The relationship between adoption and cancer may seem distant. Infertility, however, is oftentimes a consequence of cancer treatment, rendering cancer survivors incapable of biological reproduction. For this reason, the growing population of cancer survivors has a distinct relationship with adoption, as it may provide their only opportunity to parent. It is estimated that 1,479,350 men and women will be diagnosed with cancer in 2009. Remarkably, the overall 5-year relative cancer survival rate for 1999–2005 was 66.1% [1]. Since both cancer incidence rates and cancer survival rates are on the rise, the growing population of cancer survivors will likely be faced with the long-term consequences of their disease treatment, including infertility.

Research regarding the potential to become an adoptive parent post-cancer is scarce. In the one existing study that examines adoption among cancer survivors, Rosen discovered that, among a convenience sample of 11 cancer organizations, 6 international adoption agencies, and 7 adoption specialists, adoption agencies identified their chief concern as the welfare of the child and demonstrated reluctance to discuss how a cancer survivor would be viewed as a potential adoptive parent [2]. Rosen concluded that cancer patients lack access to information about adoption and may face discrimination in domestic and international adoption.

In this analysis of domestic and international adoption agencies, we aim to delve further into the intersection of adoption and cancer by looking into how prospective adoptive parents who are cancer survivors navigate the adoption process and by identifying laws and legislation that may aid or hinder them in their journey to adopt a child. We also explore legislation regarding the potential to adopt for individuals with other chronic diseases and specific lifestyle circumstances to assess how cancer survivors fit within the overall adoption system. Using information gained from agency interviews as well as personal accounts of cancer survivors, we will attempt to determine if cancer survivors face discrimination in the adoption process and, if so, characterize their experience and the barriers they may face. Finally, we argue for equal and just treatment for cancer survivors in the adoption system.

#### Adoption in the United States

In the United States, there are three kinds of domestic adoption: public agency adoptions, which are state-licensed and usually run by state or city governments; private agency adoptions, which are also state licensed and usually incorporated in a not-for-profit form and privately managed; and independent adoptions, which involve the direct placement of a child, usually with the aid of a facilitator [3]. These various types of adoption agencies all provide the link between children in need of a home and prospective adoptive parents, assessing parental capabilities as well as assisting in the legal process and court applications. All adoption agencies have requirements mandating that prospective parents meet certain criteria in order to be eligible to adopt a child. The first step in the eligibility process is usually a home study, and most states require additional background checks and probationary placement periods along with age and health requirements thereafter. Just as adoption agency structure is varied, preferences, policies, and requirements regarding prospective parents differ considerably across agency lines.

Both domestic and international adoptions are available to individuals pursuing adoption in the US, and Americans take advantage of both types. In 2000, there were 2,058,915 adopted children in the United States, or 2.5% of all children [4]. Although adoption remains relatively rare, it is still an important means to parenthood for a variety of individuals. Domestic adoption prevails as the dominant form of adoption in the US, with 87% of adopted children in the US born domestically [4]. Domestic adoption, however, has become increasingly competitive within the United States, and the difficulties surrounding the process are impacting adoption trends. In many Western, industrialized countries (including the United States), contraception, abortion, and increasing numbers of single parents raising their children have limited the number of babies available for adoption. Conversely, in poorer countries of the world, war, political turmoil, and economic circumstances lead to an opposite scenario in which there are very few prospective adopters in comparison with the vast number of children in need of a home [5]. Inter-country adoption has surfaced as a common means to parenthood for many individuals in industrialized nations, expanding options for parenthood of children from a variety of cultural and racial/ethnic backgrounds. Indeed, the United States has been a major receiving country for inter-country adoptees since World War II, and the US is characterized as the number one “receiving” country for transcontinental adoptions [6–8]. Between 1998 and 2008, the number of children adopted from other countries has increased from 15,583 to 17,438 [9]. In 2008, the largest number of international adoptions to America came from Guatemala (4,123), followed by China (3,909), Russia (1,861), Ethiopia (1,725), and South Korea (1,605) [10]. As domestic adoptions within the US have become more competitive, international adoptions have gained prevalence in recent years, offering many individuals increasing opportunities to create their family.

### **Adoption and the Law: United States**

The law, both in policy and practice, shapes the meanings and definitions of adoption within the United States. The dominant legal mode for the transfer of children in the US is plenary adoption, in which children are fully transferred from one set of parents to another [7]. Since abandoning a child is considered a crime in most legal systems

(although some jurisdictions permit a form of legal abandonment in which the mother remains anonymous), adoption was created as a formal process to allow parents to legally absolve themselves of responsibility for their child, transferring this responsibility instead to a willing individual or family [11]. Adoption law essentially creates a legal parent–child relationship between persons who have no biological relationship, based on the assumption that this arrangement is in the best interests of the child [12].

The “best interests of the child” standard was established in 1865 when the Massachusetts court ruled in *Curtis v. Curtis* that “adoption is not a question of mere property. . . the interests of the minor is the principal thing to be considered” [13]. This standard is almost universally invoked in child custody cases, and although rarely defined, is the guiding principle in determining custody between two legally recognized parents [14]. In this way, state laws and adoption agencies employ the standard to justify individual’s rights to adoption, applying various interpretations of its meaning to accommodate specific individuals. The “best interests of the child” as a standard is situation-specific and, therefore, inherently ambiguous; nonetheless, it remains the guiding criterion upon which legal decisions are often made.

The vagueness of the “best interests of the child” standard is compounded in practice by the administrative structure of adoptions agencies in the US. The vast majority of non-family adoptions in the US are arranged by private, independent agencies that usually operate on a commercial or for-profit basis [13]. These independent agencies are generally lightly regulated and characterized by wide variability in terms of policies, practices, and procedures. Consequently, adoption remains a complicated construct within the legal system of the United States. In fact, there is no national legal framework governing the adoption process, with matters of law and policy determined separately by each of the 50 states and the District of Columbia [13]. A few umbrella pieces of legislation along with related judicial decisions bring a degree of national foundation for adoption in the legal realm, but statute law, policy, and practice in relation to adoption are largely determined at the state level.

As with all aspects of family law, the Constitution (particularly the 13th, 14th, and 15th Amendments), together with the Bill of Rights, has influenced the development of adoption law within the United States [13]. In the case of adoption, the US Constitution does not provide a fundamental right to adopt, and court challenges to the constitutionality of these restrictions have not worked thus far [15]. A number of core legislative documents, however, have shaped adoption in the US, addressing various facets of the adoption process including post-legal services for birthparents, protection and services to children placed across state lines, safe havens for child abandonment, etc.<sup>1</sup> On an international level, documents such as the Hague Convention, the UN Declaration on Adoption and Foster Care, and the Child’s Right to Grow Up in a Family: Guidelines for Practice in National and Inter-country Adoption and Foster Care, emphasize the rights of the child as a state resource and, subsequently, the state’s obligation to protect this resource [16]. These aforementioned legislative pieces build a

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<sup>1</sup> As cited, these legislative documents include The Birthplace Assistance Act, The Interstate Compact on the Protection of Children, and The Safe Haven Laws, respectively [13].

small (and vague) framework for adoption, outlining various rights for the child, biological parents, and adoptive parents, but leaving the majority of legislative governing at the hands of individual states and countries.

As adoption is the prerogative of individual states rather than the US government, each state can pick and choose what components of these legislative pieces they want to invoke into practice for their constituents, creating a vague and indeterminate state-by-state legal system for adoption. The aforementioned administrative structure of adoption agencies further exacerbates this variability in that private adoption agencies, largely unregulated at the state level, can impose their own adoption policies and procedures. In this way, there are no clear definitions of what criteria define a prospective adoptive parent as “fit” for a domestic adoption.

Individuals pursuing international adoptions are burdened with another layer of inconsistent regulations: to adopt a foreign child, an individual must satisfy the laws of the sending country and United States immigration law, on top of the laws of the state where he or she lives [5]. Although the US governmental structure imposes a degree of regulation in intercountry adoption, the exchange is essentially a private legal matter between individuals looking to adopt and a foreign court operating under its respective country’s laws and regulations [12]. Some countries have a more structured system, with defined bilateral treaties or various agreements designed to govern adoption between a particular sending and a particular receiving country, but most inter-country adoption remains regulated at the adoption agency level [5].

Distinct efforts have been made to safeguard inter-country adoptions, including The 1989 United Nations Convention on the Rights of the Child and the 1993 Hague Conference’s Convention on Protection of Children and Cooperation in Respect to Inter-country Adoption, which state that an ethical adoption policy should privilege domestic adoption over international adoption whenever feasible within a reasonable amount of time [17]. The Hague Convention further aims to prevent the abduction, sale of, or traffic of children, working to ensure that inter-country adoption adheres to the aforementioned “best interests of the child” standard. However, the Convention only covers contracting states, with children of non-contracting states left unprotected. As of 2008, the Convention has been ratified by 76 countries [18].

The general lack of sound policies for inter-country adoptions has translated into a largely unregulated international system that, although founded upon the “best interests of the child” standard, lacks consistency in implementation. Indeed, legislators have failed to develop systematic policies to protect children within the international adoption system, nor have they been able to put institutional mechanisms in place to guarantee protection of these children [11]. This largely unregulated system may explain why home studies performed for international adoptions are often considered less rigorous than those for domestic adoptions [12]. In this way, inter-country adoptions may appear to be a more feasible route for cancer survivors, with certain sending countries exhibiting more permissive requirements than others.

## **Existing Discrimination in the Adoption Process**

Per the above discussion, the adoption process is complicated and difficult to navigate even without a potentially stigmatizing medical condition. On the domestic level, states vary with regard to factors they consider as disqualifying one's ability to adopt, with home visits and individual evaluations often entailing subjective evaluations by variable adoption agency employees. While agencies generally prefer well-off married couples as adoptive parents, some states have outright bans against individuals based on specific lifestyle and/or socioeconomic characteristics.

For example, at least six states (including Florida, Mississippi, Arkansas, Utah, Nebraska, and Minnesota) explicitly restrict adoptions by gays and lesbians. Other states' legislation attaches parental rights to birth certificates and does not allow two parents of the same sex on birth certificates, thus impeding adoption by gay and lesbian couples in an indirect way [7]. At the international level, discrimination based on lifestyle and partnership preferences is prevalent and variable. Some countries allow single individuals to adopt while others require a heterosexual marriage partnership. In a notable case against France in February 2002, the European Court of Human Rights held that allowing or disallowing gay and lesbian adoption was up to individual countries [19]. Sweden, Spain, and Iceland allow adoptions by gay and lesbian couples. Conversely, gay or lesbian couples cannot adopt children from Columbia, Eritrea, Estonia, Ethiopia, Ghana, India, Kenya, Kyrgyzstan, Lesotho, Marshall Islands, Panama, Rwanda, or Togo. In this way, various lifestyle characteristics can disqualify potential adoptive parents from the adoption process, denying them the opportunity to parent.

Socioeconomic prejudice is prevalent as well. China has specific income requirements, demanding that the total value of family assets must be at least \$80,000 [10]. Most domestic and international agencies simply state that prospective adoptive parents must be financially secure and prove their financial stability. By not specifically defining financial security, these agencies rely on subjective assessments by adoption agency employees, thus opening opportunities for discrimination against potential parents.

In terms of the health status of prospective adoptive parents, international agencies are explicit regarding medical disqualifiers for adoption. Individuals cannot adopt from China if they have a number of health conditions, including AIDS, severe facial deformation, and severe diseases that require long-term treatment and that may affect life expectancy (including malignant tumors). Additionally, China will not permit individuals with a BMI of 40 or more to adopt a child. Third- or fourth-stage cancers can prevent individuals from adopting from Lithuania, and persons with "various forms of cancer" cannot adopt from Moldova [10]. No countries, however, specifically mention cancer history as a disqualifier, but rather rely on ambiguous health assessments to determine that the individual is medically "fit" to take on the responsibility of an adoptive parent.

## **Interpreting the Law: Adoptive Potential of Cancer Survivors**

Statewide variability in adoption policy creates ambiguity in defining who is medically “fit” to serve as an adoptive parent. Individual adoption agencies are generally permitted to use their own discretion in evaluating the health status of adoptive parents, with a variety of legal documents and specific procedures commonly used to assess the health status prospective adoptive parents.

The Uniform Adoption Act (UAA) (1994) serves as the template for adoption statutes in most US states and can be introduced and passed in whole or part by each state legislature; to date, the majority of states have rejected the document. The UAA leaves the health status of prospective adoptive parents largely unaddressed: Section 2-203 contains a brief statement about the evaluation of prospective adoptive parents, stating that a pre-placement evaluation must contain information about “physical and mental health, and any history of abuse of alcohol and drugs” [20]. Interestingly, the UAA contains extensive requirements regarding health information of the individual adoptee as well as the biological parents of the adoptive child. Cancer survivors as potential adoptive parents are not addressed in this umbrella legislation, leaving the fate of these individuals as adoptive parents up to the jurisdiction of individual adoption agencies.

Related legislation on disability broadly defines cancer survivors as a protected population, stating that applicants who are disabled cannot be excluded from consideration as adoptive parents merely on the basis of their disability. Indeed, the Americans with Disabilities Act (ADA) defines a person as disabled if he or she “has survived cancer in the distant past” [21, 22]. In this way, cancer survivors should be protected in the adoption process. However, the ADA is not routinely enforced and the rights of a disabled individual pursuing adoption have been denied by the court in at least one notable case. In *Adams vs. Monroe County*, the court dismissed an action initiated by a blind woman, supporting the right of adoption and foster care agencies to take physical disability into account as a “legitimate consideration” when assessing an individual’s fitness to become an adoptive or foster parent, with the caveat that the agency does not routinely exclude disabled applicants from consideration by reason of their disability [23]. In this way, although the ADA protects cancer survivors on paper, in practice the act holds little merit, with the ultimate discretion for determining parental fitness falling under the responsibility of individual adoption agencies.

As the impact of cancer history on an individual’s potential to serve as an adoptive parent is largely unaddressed and unregulated at the federal and state levels, we turned to the agency-level to gauge whether individual agencies have policies or procedures in place for this unique population. We contacted both domestic and international adoption agencies to determine their perspectives and policies on the potential to parent post-cancer. While existing laws and regulations point to potential discrimination on paper, the impact of these policies in practice is unknown. Our analysis adds another layer to the examination of the potential to parent post-cancer, incorporating both adoption agency policies as well as cancer survivor experiences with the adoption process.

## **Methods**

A 13-item questionnaire was developed to examine existing adoption agency perspectives, policies, and procedures toward the potential to parent post-cancer. Along with basic demographic characteristics of the agencies such as location, size, and religious affiliation, the questionnaire inquired into whether adoption agencies screened potential parents based on health or lifestyle characteristics, and whether or not the agency currently had a policy in place for individuals with a cancer history. The questionnaire was approved by the Institutional Review Board (IRB) of Northwestern University. Twenty-seven agencies were contacted, representing 21 states throughout the US. All agencies were found through the Child Welfare Information Gateway: National Foster Care & Adoption Directory.<sup>2</sup> Private-domestic, private-inter-country, and public adoption agencies were searched for by state. All agencies were contacted via telephone. For purposes of geographic diversity, once an interview was obtained from an agency in one state, no more agencies from that state were contacted. However, if a representative from an agency returned a call and agreed to be interviewed, the interview was accepted, even if the agency was from a state that was already represented in an interview.

We spoke with a variety of agency personnel, including executive directors, directors, counselors, case workers, coordinators, social workers, family specialists, administrative assistants, and child protection specialists. Out of twenty-seven agencies, twenty three agencies self-identified as private, while four self-identified as public. Eight agencies (30%) offered domestic adoptions only, three agencies (11%) offered international adoptions only, and sixteen agencies (59%) offered both domestic and international adoptions. The international agencies adopted from a combined 20 different countries across the globe. Financially, the average cost for agencies offering domestic adoption only was lowest (\$16,062.50), compared with agencies offering international adoption only (\$19,722.30) and agencies offering both domestic and international adoptions (\$21,058.00). On average, the agencies completed 93 adoptions per year. Five agencies, or 27% of the agencies contacted, indicated a religious affiliation. Of those who self-identified as religiously affiliated, three agencies identified as Christian, one agency identified as Catholic, and one agency identified as mainline/liberal protestant. Although the sample is relatively small, we aimed for diversity in size, geography, and religious affiliation.

Additionally, we joined an informal online support group for cancer survivors who are interested in or have pursued adoption. Our membership in this group and access to individual experiences was approved by the IRB of Northwestern University. We used publicly available information about individual experiences with the adoption process to augment our agency-level analysis.

## **Results**

Adoption agencies were generally very vague in describing how cancer survivors would navigate the adoption process. They varied in terms of the required components of a medical status screening. Namely, four agencies required a physical only to determine the

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<sup>2</sup> The Child Welfare Information Gateway: National Foster Care & Adoption Directory can be found online at: <http://www.childwelfare.gov/nfcad/>

health status of the prospective parent. Three agencies required that a physician fill out an agency-specific medical form, and four agencies required both a physical and an agency-specific medical form. Seven agencies required a physical along with a doctor’s attestation of health and seven agencies required a physician note only. Finally, one agency explained that they complete the medical screening independently, and one agency required an entire medical history of an individual. The medical screening requirements by agency are summarized below in Table 11.1.

**Table 11.1** Medical screening requirements by agency

Medical screening requirements	
Physical only	4
Agency-specific medical form to be filled out by physician	3
Both physical and agency-specific medical form to be filled out by physician	4
Physical along with doctor’s attestation of health	7
Physician note only	7
Placement agency completes medical screening independently	1
Entire medical history	1

In terms of the relative importance of past versus current medical status of prospective adoptive parents, 15 agencies responded that they screened for both current and past medical status, 8 agencies indicated they only screened for current medical status, and 1 agency said they screened for neither.<sup>3</sup> Of the agencies that screened potential parents on their past medical history, the agencies screened an average of 17.28 years into the past.

We asked agencies whether there were any specific medical conditions that would prevent potential parents from adopting in an attempt to draw parallels between cancer and other chronic diseases and lifestyle characteristics that may exclude individuals from adoption. Eighteen agencies responded that there were no medical conditions that would disqualify potential adoptive parents while seven agencies admitted that a number of specific medical conditions would prevent individuals from adoption within their agency, citing a variety of illnesses and medical conditions that included contractible diseases, AIDS, and terminal illnesses. A complete list of the medical conditions that were mentioned is included below in Table 11.2.

**Table 11.2** Specific medical conditions that would bar potential parents from adoption, as cited by specific agencies

Specific medical condition as defined by agency
Contractible diseases
AIDS
Active, life-threatening diseases
Anti-depressants
Terminal illnesses that shorten lifespan (2)
Conditions that require a large amount of narcotics that render individual unconscious; substance addiction; severe mental conditions like schizophrenia

<sup>3</sup> Additionally, two agencies abstained from answering this question.

In terms of discrimination based on lifestyle preferences, 11 agencies indicated that specific lifestyle characteristics would prohibit individuals from adopting with their agency. These responses were related to marital status (5), sexuality (3), drug/alcohol abuse (2), and religion (1). Specifically, three agencies identified that they would not allow unmarried individuals to adopt, one agency indicated that an individual who is separated would not be allowed to adopt (they must be formally divorced), and one agency would not allow single men to adopt.

Cancer history was not specifically addressed by the majority of the adoption agencies; only one agency indicated that they have a policy in place for prospective adoptive parents with a history of cancer, and their self-described policy was rather ambiguous. The agency asserted that cancer history would be addressed during the individual home study, and the ability for the individual to adopt would depend upon how long the survivor has been in remission. The other 26 agencies did not identify a policy in place for cancer survivors, although two mentioned caveats, with one stating that an individual with a cancer history must have a reasonable life expectancy and another requiring a doctor's affirmation health. All agencies were also asked whether the number of disease-free years would be relevant in assessing a prospective adoptive parent with a cancer history. Seven agencies (26%) indicated that the number of disease-free years would be relevant, while nine agencies (33%) claimed that this information would not be important, with an additional four agencies not aware of the importance of this information and one agency claiming that the importance of the number of disease-free years would be assessed in the doctor's note.

On a related note, agencies were queried on whether they have a policy in place for prospective adoptive parents who are HIV positive. Two agencies responded positively, with one agency noting that HIV positive individuals (as determined through doctor's physical) would be disqualified from adoption and the other citing their resident state's law regarding the right to adopt for HIV positive individuals.<sup>4</sup> The remaining 25 agencies indicated that they do not currently have a policy in place for prospective parents who are HIV positive.

When asked what percentage of adoptive parents receiving children from their agency were cancer survivors, agency personnel seemed largely unaware. Individual responses are included below, with the majority of agencies stating that less than 2% of adoptive parents using their agency have a history of cancer (Table 11.3).

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<sup>4</sup> Notably, extensive research into state laws regarding the potential to serve as an adoptive parent for HIV positive individuals yielded no results. While this may indicate inadequate research, it may also reflect misconceptions among adoption agency employees as to the source of their own policies.

**Table 11.3** Percentage of adoptive parents who are cancer survivors by agency

Percentage	Number of adoption agencies (n = 27)
Zero	2
<1%	6
1-2%	2
2%	3
3-5%	1
4%	1
<5%	2
<10%	1
10%	1
Maybe 10%	1
Very low/very small	4
Don't know	3

As far as protocols for current cancer patients, three agencies indicated they have a policy in place, while 24 agencies indicated that they do not. The three agencies' policies for current cancer patients include a requirement for a doctor's statement that the individual's lifespan would not be shortened, a conversation with the patient's primary doctor and oncologist, and a stipulation that the patient suspends the adoption process until treatment is complete.

In an attempt to gauge how these adoption agencies wanted to be perceived regarding their positions on cancer survivors as adoptive parents, we borrowed a question from Rosen's initial study, asking all agencies whether they would like to be known as a cancer friendly agency. Nineteen agencies (70%) responded yes, four (15%) responded no, three (11%) were unsure, and one agency (4%) did not respond. On a related note, 22 agencies agreed that cancer survivors should reveal their cancer history, 3 agencies stated that a cancer survivor should not reveal his/her history, and 2 agencies stated that this decision is up to the individual applying for adoption.

## Discussion

Various types of discrimination are apparent in the adoption process, with certain medical conditions and lifestyle characteristics disqualifying individuals (as evidenced by both legal proceedings and agency policies) from adopting children in different states and from agencies throughout the United States and abroad. As earlier described, there are no specific legislative documents in the United States that categorically prohibit cancer survivors from serving as adoptive parents to a child in need. This fluctuating prejudice against cancer survivors speaks to the informal process in which adoption agencies can essentially pick and choose who they accept as reasonable adoptive parents. The inherent structure of the adoption process facilitates this complication. Adoption in the US operates with the same free-market ethos as other commodity exchanges, with adoption placements not subject to a tight regulatory system; consequently, the exchange of children operates through a mixture of official law and its interpretation, discussion, and rights claims [7, 13]. An individual with a clean medical history competing against a cancer survivor to adopt a child would arguably receive preferential treatment, based both on the aforementioned "best interests of the child" standard as well as the relative

freedom adoption agencies have in choosing adoptive parents. In this way, although cancer survivors are not specifically disfavored against in writing, they are subject to the market exchange ethos of the adoption process, and therefore, subject to open and consistent prejudice in trying to adopt a child.

Although existing legislative documents such as the Americans with Disabilities Act (ADA) protect cancer survivors' rights to adopt a child, these protections are largely inconsequential in practice. As evidenced by the court decision to rule in favor of the adoption agency to discriminate against the blind woman trying to adopt, the ADA often provides little protection in application [23]. Cancer survivors, like many other marginalized populations, are left to fend for themselves against discrimination in the adoption process, with no official or reliable legal protections granted to them. While the legal analysis points to the protections lacking for cancer survivors, the adoption agency analysis highlights the various ways in which cancer survivors may face discrimination.

As previously described, the network of adoption agencies working with potential parents in the US is characterized by fundamental variability and ambiguity. In terms of the health status of prospective parents, all agencies required some form of medical screening, ranging from physicals to agency-specific medical forms to doctor's attestations of health to entire medical histories. These stipulations, required either individually or in combination, are also innately subjective. Individual physicians are allowed to determine what kind of information is relevant to an individual's potential to parent, with doctors using their discretion to determine medical fitness to parent. Even when agencies do require specific medical forms, these vary significantly from one agency to the next. We were granted access to two different medical forms required by agencies involved in our study. The first form inquired about general health status including allergies, obesity, and heart disease; the only place where cancer could feasibly be addressed was in the section asking about past hospitalizations and history of previous diseases. But, as with doctor's notes, all information on the specified form is subject to physician interpretation. The second medical form was far less comprehensive than the first, with cancer history likely addressed in a section asking about the patient's medical history as well as the following question (as presented to the physician): "Is this patient's life expectancy normal?" The remaining agency-specific medical forms that we were not granted access to view presumably cover the same broad range of topics, probing into a patient's medical history, but not directly asking for cancer history. Therefore, it is clear that among the agencies interviewed, cancer history in and of itself is not a distinct component in the evaluation of an individual's medical history.

Specific medical conditions that disqualify an individual from adoption, as noted by adoption agency personnel, include a variety of health conditions such as AIDS, active life-threatening diseases, and terminal illnesses expected to shorten lifespan (See Table 11.2). Cancer history could arguably be implicated in the "terminal illnesses expected to shorten lifespan" category, although this claim could be refuted by the argument that in the case of many cancer survivors, the illness is clearly not terminal, as they are currently alive and disease-free. The minority of survivors who do relapse, however, could be characterized as having a "terminal illness," depending upon their specific diagnosis.

The apparent lifestyle discrimination, as supported by courts both domestically and internationally, was supported in our analysis of individual adoption agencies. Agency personnel identified marital status, sexuality, drug/alcohol abuse, and religion as potential disqualifiers for individuals using their agency. Interestingly, these forms of discrimination are both transparent and accepted, pointing once again to the negative implications for marginalized populations as generated by the free market system of adoption in the US.

Explicit prejudice against cancer survivors was less obvious in this sample: only one agency indicated that they have a policy in place for cancer survivors, stating that the individual's health would be addressed in the home study and their eligibility to adopt a child would depend upon how long the survivor had been in remission. Interestingly, the type of cancer, stage at diagnosis, and other relevant medical conditions were not cited as necessary information in interpreting an individual's cancer history. Instead, in this instance, the number of disease-free years truly determined a cancer survivor's potential to adopt. Further, a greater number of agencies (9) claimed that the number of cancer-free years would not be important in determining parental eligibility than the number of agencies that claimed that these numbers would be important (7). Adoption agencies do not have specific policies that protect or prohibit cancer survivors from adopting, leaving cancer survivors vulnerable to potential informal discrimination. Although harder to prove, this informal discrimination is supported by the general lack of knowledge about cancer survivorship made apparent during conversations with agency personnel.

For example, when asked what percentage of adoptive parents who have successfully adopted a child from their agency are cancer survivors, agency employees were relatively unaware but indicated that it was a very small amount. The fact that agencies are not acutely aware of cancer survivors within their system could be due to the fact that few cancer survivors have approached their agency, or, conversely, that cancer survivors have not made it past the medical screening portion of the adoption process. Indeed, during an interview with one of the agencies, we were provided with anecdotal evidence that there had been a case where a couple affected by cancer had difficulty adopting from a competitor agency. This was the only specific case that was referenced in regard to cancer survivors; no cases of successful adoption by cancer survivors were presented to the researchers by adoption agency personnel.

This general lack of information from adoption agency personnel is in sharp contrast with a general desire (on behalf of the adoption agencies) to be known as a cancer-friendly agencies. Although these agencies would like to be known as cancer-friendly, they are not explicit in their policies regarding adoption by cancer survivors, thus effectively permitting discrimination against cancer survivors, a bias that is further facilitated by the variability and subjectivity in their assessments of parental fitness. This discrepancy may stem from individual agencies wanting to be perceived positively by the public and to shy away from claims of prejudice against any marginalized group. We are not arguing that all adoption agencies discriminate specifically against cancer survivors, but rather that the current adoption system permits informal prejudice in practice that likely varies from one

agency to the next. In this way, the inherent subjectivity in screening for prospective adoptive parents likely means that cancer survivors seeking adoption may be successful in one agency but unsuccessful in another.

Birth mothers can also play a role in discriminating among potential adoptive parents. In the majority of independent placements, birth mothers determine the ultimate suitability of adopters, and therefore, can openly disfavor against cancer survivors. The right of a birth mother to place her child for adoption with whomsoever she chooses, or to authorize another person to do so on her behalf, has been embodied in the laws of all but four states<sup>5</sup> [20]. The exact influence of a birth mother's preference, however, is hard to characterize on a broad level, as birth mothers often relinquish their rights to private agencies in the context of private adoptions. In the case of public adoptions, the rights of the birth parents are often judicially terminated, with government agencies thus shouldering the responsibility of placement decision making. Based on the form of adoption they use, therefore, birth parents can freely exercise their own discretion in choosing adoptive parents, adding another potential opportunity for discrimination against cancer survivors.

### **Expanding the Discussion: The Experience of Potential Adoptive Parents**

While agency interviews unveiled informal policies, perspectives, and general practices, individual accounts from prospective adoption parents added another layer of support to this analysis. In establishing contact with an informal online support group for cancer survivors considering adoption, we gathered some anecdotal evidence on actual experiences with the adoption process. A couple with a cancer history shared their experience with adoption, indicating that they had tried dual approaches in informing agencies of their cancer history – both upfront honesty as well as vague avoidance of the subject – with both approaches ultimately unsuccessful. Another cancer survivor passed along recommendations that agencies willing to work with single parents and same-gendered couples seem more open to accepting cancer survivors as adoptive parents, speaking once again to variable discrimination as presented by some agencies but not others.

A breast cancer survivor described her multiple attempts at adoption, first trying an open, honest approach about her cancer history, only to be turned down in the early stages, and trying again with a more vague approach, but denied once her doctor mentioned her cancer history. In the words of the survivor herself, cancer survivors are often lost in the adoption process, lacking practical information about how to share their cancer history with an adoption agency and subject to intense emotional distress as a result of their medical history.

I have found the whole experience to be an emotional roller coaster that mostly has lows.  
I feel like I am being discriminated against because of my health. I haven't made it very far in the adoption process but we are still trying [. . .] I wish there was a step by step guide about how to adopt with cancer. It's like a big black hole that you are blindly trying to crawl out

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<sup>5</sup> Colorado, Connecticut, Delaware, and Massachusetts.

of. Sometimes you get glimpses of light, but most of the time you are in total darkness.

The real experience of cancer survivors in the adoption process is not described as a pleasant one, but rather a discouraging process in which individuals feel hindered by their health history. Cancer survivors who have attempted adoption express frustration with the process and the intra-country inconsistencies and inter-agency variations regarding their potential to parent. As described by a female cancer survivor who has been waiting on an international adoption for over a year, agencies themselves are often ambiguous about their own rules, and discrimination against cancer survivors is open and apparent:

The other thing that bothered us was the variety of answers we heard about a particular country's rules regarding international adoption and cancer – some agencies said the rules were the country's, some said the were agency rules, and in some cases it wasn't clear [. . .] Someone told me recently that it's illegal for agencies to discriminate against a family based on a cancer diagnosis. If that is true, there is a lot to be done in that area particularly with agencies that deal with international adoption, because there is whole sale discrimination and misinformation out there. It's also nearly impossible to get a good idea of what your options (internationally) are without a lot of research, and a lot of guesswork based on many, many phone calls. It would be helpful if agencies would provide clear information about their program's cancer rules or at least have a written policy about how they will handle survivors of cancer.

Not only are cancer survivors at a distinct disadvantage in the adoption process, but they are also lacking information about their rights to adoption. Adoption agency policies are difficult to locate and interpret, leaving cancer patients deprived of the information and facts they need to most easily pursue an adoption.

Adoption after cancer, however, is a possibility, as evidenced by an account of a successful adoption by a breast cancer survivor. Just 2 years after her diagnosis, a woman and her husband adopted a 14-month-old through an international agency. Although they were eventually able to adopt, the road to their adoption was not straightforward. The woman and her husband attempted adoption through several agencies in the same foreign country, with a number of agencies prohibiting her from adoption based on her medical history. The agencies that rejected their request cited an alleged country-wide cancer policy, even though the couple eventually adopted a child from this same country.

The only difficulty and frustration that I experienced as a cancer survivor was being rejected by some adoption agencies based on their own cancer history policy, which claimed to be [the country's] policy

As seen in our own analysis, adoption agency employees are often unaware of their own policies and procedures regarding the health of prospective parents – this general lack of information permits informal prejudice against cancer survivors in the adoption process.

### **Defining the Discrimination**

In sum, there is evidence that cancer survivors face de facto discrimination when navigating the adoption process, discrimination that is not present systemically but rather in isolated agency cases. Inherent variability in the adoption system, state policies, and individual medical assessments means that this discrimination can surface in various forms at various points in the process. One survivor may be denied outright, while another may face exclusion during the home study and another during a doctor's examination, while a fourth may get a lucky break and successfully adopt a child.

This form of discrimination is, by definition, difficult to define, and even harder to prove. However, the information gathered from the legal analysis, combined with the adoption agency surveys and personal accounts all speak to the potential for discrimination against and the lack of protection for cancer survivors as adoptive parents. Cancer survivors are not a protected population nor are there any specific policies that prevent them from adopting, but the current interagency variability contributes to discrimination in practice. Informal, inconsistent discrimination against cancer survivors is manifested on a case-by-case basis during the adoption process.

A number of limitations may have influenced the findings from the adoption agency analysis. The relatively small sample size ( $n = 27$ ) may make it difficult to draw significant conclusions from the data. Our sample was also largely composed of private agencies ( $n = 23$ ), with only four agencies representing the public sector. Finally, religious affiliation may understandably impact adoption agency policies and procedures; including a more religiously diverse sample could have strengthened our analysis. There was also wide variety in the knowledge, expertise, training, and experience of the agency personnel whom we interviewed. Because we interviewed anyone who was willing to speak with us, our interviewees included a diverse group of employees. The position and perspectives of the individuals whom we spoke with influenced their responses, which may have biased our results. Finally, this study only takes into account the perspectives of the adoption agencies and a handful of adoptive parents, but no birth parents. This analysis points to the need for a larger, more extensive, and detailed study of cancer survivors in the adoption system to include an emphasis on individual experiences and the perspectives and preferences of birth parents. Despite these limitations, we are confident that our analysis provides a novel description of the adoption process, underscoring the difficulties faced by cancer survivors pursuing adoption.

## **Conclusions**

De facto discrimination pervades the adoption process for cancer survivors, manifesting itself at various points of the adoption process and through various mechanisms. Although documents and legal protections (such as the ADA) define cancer survivors as a protected class and thus prevent against discrimination in the adoption system on paper, these protections are ineffective in practice. As the majority of adoption agencies do not have specific policies in place to define how they handle prospective adoptive parents with a cancer history, cancer survivors experience varying forms of informal discrimination, as evidenced by individual accounts and narratives as well as adoption agency interviews.

Arguing for a more defined policy for prospective adoptive parents who are cancer patients is a double-edged sword. While this call could bring protection to individuals and secure their right to adopt, it could also result in blanket discrimination that prevents individuals from adoption. As such, the variability of the status quo permits prospective parents to “shop around,” just as it permits agencies to pick and choose (even if arbitrarily) adoptive parents. Thus, it is difficult to gauge which system would provide the most protection for cancer patients, as the current interagency variability may allow persistent cancer survivors to eventually locate an agency who will approve their request for a child. As previously demonstrated, protective documents and policies do not ensure safeguarding in practice. Within the current adoption system, cancer survivors are recommended to adequately research a multitude of adoption agencies in their effort, and to not give up after the first sign of dissent, as the variability in policies and practice may eventually prove to their benefit.

The implications of this de facto discrimination in the adoption system carry over into cancer patient clinical care. Since adoption is not a guaranteed option for cancer survivors, individuals facing a diagnosis may be urged to protect their biological capacity to reproduce in case adoption proves impossible. In this way, fertility preservation technologies may provide cancer patients with a back-up option in the face of uncertain adoption outcomes, enhancing the potential to parent post-cancer.

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