

Daniel Hauser Case
Closing Arguments Contribution
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Overview

The treatment being prescribed by Dr. Bostrom to treat Daniel Hauser's diagnosis of Hodgkin Leukemia (Stage IIB) is one of the standards of care for this disease, has a high success rate and may be the best course of treatment for Daniel's ailment. However, the favorable results are offset by acute and long-term, treatment-associated toxicities^(Hodgson, 2007) – making the decision to take this treatment very difficult for the patient. This treatment is associated with severe, permanent, long term morbid and potentially fatal side effects of the therapy, including: anemia, bowel problems, fatigue, leucopenia, thrombocytopenia, and neutropenia; infection and fever; anemia, depression, pain, nausea and vomiting, hair loss, and gastrointestinal and pharyngeal toxicity.^(NCI, 2009; Eich et. Al, 2005), cardiac and pulmonary toxicity resulting in excess long-term mortality (increased risk for up to 25 years) as a result of myocardial infarction,^(Swerdlow et al, 2007; Myrehaug et al., 2008) growth and neuroendocrine dysfunction,^(Sklar, 1997), permanent gonadal injury resulting in infertility,^(Hudson and Donaldson, 1999; Hobbie et al, 2005) and increased mortality from secondary cancers.^(Diehl, 2007) In risk based treatment, the risks of the treatment must be weighed against the possible benefit of the treatment. Because remission can be achieved in most patients, the principal challenge to pediatric oncologists is obtaining remission while minimizing the detrimental effects on quality of life of the survivors.^(von der Weid, 2008) The Patient's Bill of Rights and principles of informed consent to treat and medical ethics have been circumvented in this case. The patient/parent needs to be given the freedom and their right preserved to explore complementary and alternative medicine (CAM) options for the treatment of cancer. Daniel should not be forced to undertake treatment based on this single diagnosis. This treatment poses significant risk of long-term, permanent toxicity that result in considerable impairments on quality of life and increased risk of later death. The patient/parent has the right to understand and assess the risks and benefits associated with this treatment.

Patients' Bill of Rights

Documents stating the patients' rights and responsibilities have been drafted by numerous government agencies and non-government organizations to protect the rights of the patient, and support their recovery. The Consumer Bill of Rights and Responsibilities was adopted by the U.S. Advisory Commission on Consumer Protection and Quality in the Health Care Industry in 1998. It is also known as the Patient's Bill of Rights.^(ACS, 2009)

The Patient's Bill of Rights was created with the intent to reach 3 major goals:

1. *to help patients feel more confident in the U.S. health care system; the Bill of Rights:*
 - *assures that the health care system is fair and it works to meet patients' needs*
 - *gives patients a way to address any problems they may have*
 - *encourages patients to take an active role in staying or getting healthy*

2. *to stress the importance of a strong relationship between patients and their health care providers*
3. *to stress the key role patients play in staying healthy by laying out rights and responsibilities for all patients and health care providers*

This Patients' Bill of Rights focuses on hospitals and insurance providers, and conveys seven key rights to the patient:

1. ***Information disclosure.*** *You have the right to accurate and easily-understood information about your health plan, health care professionals, and health care facilities. If you speak another language, have a physical or mental disability, or just don't understand something, help should be given so you can make informed health care decisions.*
2. ***Choice of providers and plans.*** *You have the right to choose health care providers who can give you high-quality health care when you need it.*
3. ***Access to emergency services.*** *If you have severe pain, an injury, or sudden illness that makes you believe that your health is in serious danger, you have the right to be screened and stabilized using emergency services. You should be able to use these services whenever and wherever you need them, without needing to wait for authorization and without any financial penalty.*
4. ***Participation in treatment decisions.*** *You have the right to know your treatment options and take part in decisions about your care. Parents, guardians, family members, or others that you select can represent you if you cannot make your own decisions.*
5. ***Respect and non-discrimination.*** *You have a right to considerate, respectful care from your doctors, health plan representatives, and other health care providers that does not discriminate against you.*
6. ***Confidentiality of health information.*** *You have the right to talk privately with health care providers and to have your health care information protected. You also have the right to read and copy your own medical record. You have the right to ask that your doctor change your record if it is not correct, relevant, or complete.*
7. ***Complaints and appeals.*** *You have the right to a fair, fast, and objective review of any complaint you have against your health plan, doctors, hospitals or other health care personnel. This includes complaints about waiting times, operating hours, the actions of health care personnel, and the adequacy of health care facilities.*

The American Hospital Association has a list of rights along with patient responsibilities that can help a person be a more active partner in his or her health care. (ACS, 2009) Recently, the American Hospital Association replaced their Patient's Bill of Rights with the *Patient Plan Partnership*, which contains several sections covering the interactions between patients and hospitals. (AHA, 2009)

The sections explain some of the basics about how you can expect to be treated during your hospital stay. They also cover what we will need from you to care for you better. If you have questions at any time, please ask them. Unasked or unanswered questions can add to the stress of being in the hospital. Your comfort and confidence in your care are very important to us.”

Involvement in Your Care

Discussing your medical condition and information about medically appropriate treatment choices. To make informed decisions with your doctor, you need to understand:

- *The benefits and risks of each treatment.*
- *Whether your treatment is experimental or part of a research study.*
- *What you can reasonably expect from your treatment and any long-term effects it might have on your quality of life.*
- *What you and your family will need to do after you leave the hospital.*
- *The financial consequences of using uncovered services or out-of-network providers.*
- *Please tell your caregivers if you need more information about treatment choices.*

Understanding your health care goals and values.

You may have health care goals and values or spiritual beliefs that are important to your well-being. They will be taken into account as much as possible throughout your hospital stay. Make sure your doctor, your family and your care team know your wishes.

The Minnesota Patient's Bill of Rights (see Appendix) states:^(MNDH, 2007)

It is the intent of the Legislature and the purpose of this statement to promote the interests and well-being of the patients of health care facilities. No health care facility may require a patient to waive these rights as a condition of admission to the facility. Any guardian or conservator of a patient or, in the absence of a guardian or conservator, an interested person, may seek enforcement of these rights on behalf of a patient. An interested person may also seek enforcement of these rights on behalf of a patient who has a guardian or conservator through administrative agencies or in probate court or county court having jurisdiction over guardianships and conservatorships. Pending the outcome of an enforcement proceeding the health care facility may, in good faith, comply with the instructions of a guardian or conservator. It is the intent of this section that every patient's civil and religious liberties, including the right to independent personal decisions and knowledge of available choices, shall not be infringed and that the facility shall encourage and assist in the fullest possible exercise of these rights.

It is declared to be the public policy of this state that the interests of each patient be protected by a declaration of a patient's bill of rights which shall include but not be limited to the rights specified in this statement. Patients shall, at admission, be told that there are legal rights for their protection during their stay at the facility or throughout their course of treatment and maintenance in the community and that these are described in an accompanying written statement of the applicable rights and responsibilities set forth in this section. Current facilities policies, inspection findings of state and local health authorities, and further explanation of the written statement of rights shall be available to patients, their guardians or their chosen representatives upon reasonable request to the administrator or other designated staff person, consistent with chapter 13, the Data Practices Act, and Section 626.557

The following paragraphs (6, 7, 9, 17, and 21) of the American Hospital Association's Patient Care Partnership covers the patient's rights and responsibilities that are pertinent to this case:^(AHA, 2009)

6. Information about Treatment

Patients shall be given by their physicians complete and current information concerning their diagnosis, treatment, alternatives, risks and prognosis as required by the physician's legal duty to disclose. This information shall be in terms and language the patients can reasonably be expected to understand. Patients may be accompanied by a family member or other chosen representative, or both. This information shall include the likely medical or major psychological results of the treatment and its alternatives.

7. Participation in Planning Treatment

Notification of Family Members:

(a) Patients shall have the right to participate in the planning of their health care. This right includes the opportunity to discuss treatment and alternatives with individual caregivers, the opportunity to request and participate in formal care conferences, and the right to include a family member or other chosen representative, or both.

9. Right to Refuse Care

Competent patients shall have the right to refuse treatment based on the information required in Right No. 6. In cases where a patient is incapable of understanding the circumstances but has not been adjudicated incompetent, or when legal requirements limit the right to refuse treatment, the conditions and circumstances shall be fully documented by the attending physician in the patient's medical record.

17. Grievances

Patients shall be encouraged and assisted, throughout their stay in a facility or their course of treatment, to understand and exercise their rights as patients and citizens.

21. Protection and Advocacy Services

Patients shall have the right of reasonable access at reasonable times to any available rights protection services and advocacy services so that the patient may receive assistance in understanding, exercising, and protecting the rights described in this Section and in other law. This right shall include the opportunity for private communication between the patient and a representative of the rights protection service or advocacy service.

The development of written, established patients' rights and responsibilities by legislative and medical associations provides guidelines for ethical medical treatment, and underscores the importance of respecting the patient's wishes for their treatment.

Informed Consent and Medical Ethics

In general, all invasive procedures require informed consent from the patient or guardian. Patients have a legal right to be informed of the risks and benefits of and alternatives to an invasive procedure, and they must give consent before that procedure can be performed. Patients have a legal right to withdraw consent even after a procedure has begun as long as medically viable options remain.

The American Medical Association makes the following statement regarding informed consent:^(AMA, 2009)

Informed consent is more than simply getting a patient to sign a written consent form. It is a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention.

In the communications process, you, as the physician providing or performing the treatment and/or procedure (not a delegated representative), should disclose and discuss with your patient:

- *The patient's diagnosis, if known;*
- *The nature and purpose of a proposed treatment or procedure;*
- *The risks and benefits of a proposed treatment or procedure;*
- *Alternatives (regardless of their cost or the extent to which the treatment options are covered by health insurance);*
- *The risks and benefits of the alternative treatment or procedure; and*
- *The risks and benefits of not receiving or undergoing a treatment or procedure.*

In turn, your patient should have an opportunity to ask questions to elicit a better understanding of the treatment or procedure, so that he or she can make an informed decision to proceed or to refuse a particular course of medical intervention.

This communications process, or a variation thereof, is both an ethical obligation and a legal requirement spelled out in statutes and case law in all 50 states. **Include the following?** (For more information about ethical obligations, see the AMA's Code of Medical Ethics, contained in the [AMA PolicyFinder](#). Providing the patient relevant information has long been a physician's ethical obligation, but the legal concept of informed consent itself is recent.

The first case defining informed consent appeared in the late 1950's. Earlier consent cases were based in the tort of battery, under which liability is imposed for unpermitted touching. Though battery claims occasionally occur when treatment is provided without consent, most consent cases generally center around whether the consent was "informed", i.e., whether the patient was given sufficient information to make a decision regarding his or her body and health care. Because informed consent claims, unlike battery claims, are based in negligence, they generally are covered by liability insurance.

To protect yourself in litigation, in addition to carrying adequate liability insurance, it is important that the communications process itself be documented. Good documentation can serve as evidence in a court of the law that the process indeed took place. A timely and thorough documentation in the patient's chart by the physician providing the treatment and/or performing the procedure can be a strong piece of evidence that the physician engaged the patient in an appropriate discussion. A well-designed, signed informed consent form may also be useful, but an overly broad or highly detailed form actually can work against you. Forms that serve mainly to satisfy all legal requirements (stating for example that "all material risks have been explained to me") may not preclude a patient from asserting that the actual disclosure did not include risks that the patient unfortunately discovered after treatment. At the other extreme, listing all of the risks may not be wise either. A comprehensive listing will be difficult for the patient to understand and any omission from the list will likely be presumed undisclosed. If you are using a form that contains a list, consider, with your attorney, inserting language indicating that the list is not exclusive (such as "included, but not limited to") before the list begins. Medicare participating physicians must also be cognizant of CMS's requirements for informed consent. (AMA, 2009)

In addition, the AMA's guidelines on medical ethics state, "A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, **make relevant information available to patients**, colleagues, and the public, obtain consultation, and use the talents of other health professionals when indicated."^(AMAb, 2009) The evidence in this case indicates that relevant information was not made available to the patient/parent, and these well-established medical principles of informed consent to treat and medical ethics were not followed.

The Children's Oncology Group and Long Term Follow Up of Cancer Survivors

The National Cancer Institute sponsors several cooperative clinical trials groups to study pediatric cancers, the largest of which is the Children's Oncology Group (COG). In 2000, NCI facilitated the formation of COG through a merger of the Children's Cancer Group, the Pediatric Oncology Group, the Intergroup Rhabdomyosarcoma Study Group, and the National Wilms Tumor Study Group. Because of this network, accrual to pediatric clinical trials is remarkably high: Among eligible children younger than 5, 90 percent or more are currently treated as part of a clinical trial, compared with less than 5 percent participation in trials by the adult population.^(NCI, 2008)

The Minnesota Children's Hospital is a member of the COG, and Dr. Bostrom is listed as a principle investigator. The COG recognizes the importance of issues related to cancer therapy, and especially the importance of long-term follow up (LTFU) and care. Their document, *Long-Term Follow-Up Resource Guide*, states lessons and principles for helping survivors of childhood cancer and treatment cope with long-term effects of treatment.^(COG, 2009) Full information disclosure would dictate that these same lessons and principles are related to the patient or parent considering standard cancer therapy before they agree to undertake the treatment.

The COG's Long-Term Follow Up Resource Guide states:

Parents and patients must learn to advocate for themselves in order to navigate through a lifetime of survivorship issues. Ideally, parents and patients should learn advocacy skills throughout their treatment. However, advocacy issues become essential in survivorship, since parents and patients must address important issues as they arise.^{5, 36,}

³⁷

Successful advocacy begins with education, because when parents and patients become equipped with an understanding and acceptance of survivorship issues, they become confident enough to advocate for themselves. Suggestions for assisting survivors to develop advocacy skills include:

- Make parents and patients aware that advocacy is a necessary skill, and one that will enhance survivorship*
- Discuss advocacy, including how and why to be a personal advocate, during the initial LTFU visit*
- Include the following in each subsequent LTFU visit:*
 - Discussion and assessment of advocacy skills*
 - Discussion of survivorship issues*

- Psychosocial support
- Distribution of information and resources

Essential Skills.

Four basic self-advocacy skills have been studied and identified as essential.

- Information-seeking
- Communication
- Problem-solving
- Negotiating

These skills should be taught throughout treatment and evaluated during visits to the LTFU clinic.³⁸ It is important for survivors to be proactive in developing these self-advocacy skills in order to maximize their overall health and well-being throughout the cancer experience.

Advocacy: What, Why, How?

Parents and patients may know intuitively that they should advocate for themselves. However, many do not understand the types of advocacy, why advocacy is necessary in order to navigate through survivorship successfully, and how they can become an effective advocate. An important goal for LTFU clinics is to educate survivors and their families so that they are able to make knowledgeable decisions about the future that are in their best interest.

“I knew I should stand up for my child, but I would not call myself an advocate. To me, an advocate was someone who stands up for legal or financial rights. It took me a while to learn the broad scope of advocacy and what it meant for me and my child.”

- Mary,
Parent

Characteristics of a successful advocate.

First and foremost, an advocate cares about the overall well-being of the survivor, regardless of whether the advocate is a parent or a survivor. Overall well-being includes both physical and psychosocial issues. An advocate must be willing to ask questions, proactively seek out information, and take some positive risks that will lead to greater benefit in the future. Not all patients and parents will embrace advocacy in the same way or to the same degree, but fundamental education and advocacy are necessary for all survivors. It is also important to note that an advocate who stands up for an individual survivor is also advocating for childhood cancer survivors in general. The more educated the population, the easier it will become for future survivors to function.

Unfortunately, advocacy sometimes means stepping out into an area that others have not yet explored. An advocate may experience challenges along the way, such as healthcare professionals or insurance companies that are unaware of certain issues that survivors face. Because

advocacy can at times be frustrating and discouraging, it is important for LTFU clinic staff to support advocacy efforts. The clinic should serve as a safe foundation where parents and survivors can develop advocacy skills. Part of this encouragement should include pointing out that advocacy skills can be used beyond the childhood cancer arena. The education and skills developed for advocacy related to survivorship can also be applied in other situations that arise, both at work and at home.

Types of advocacy.

While each institution has its own interests in mind, parents and patients should be educated regarding national and local childhood cancer issues and initiatives. Encourage parents and patients to get involved on a national, local, and personal level. Make them aware of programs available to discuss important issues such as, but not limited to, volunteering, fundraising, laws and legislation, treatment choices, and wellness issues. Networking serves to connect survivors and their families to a much bigger picture, which in turn often allows them to find meaning and purpose in their experiences. A list of organizations that provide information and advocacy for survivors is included in Table 8.

Promoting advocacy.

Promote advocacy skills for patients and/or parents during LTFU clinic visits. For example, structure clinic visits to allow time for questions and discussion, and for dissemination of information that will promote a better understanding of survivorship issues and ways in which to advocate. Establish an environment that is consistent, up-to-date, and comfortable. Develop a “library” of resources, including web-based technology if possible, so that parents and patients have access to information that they might not have the tools to access at home. Make the LTFU clinic a “home base” from which other resources and specialists can be accessed.

Parents and Patient Advocates.

Depending on age, diagnosis, and treatment, survivors of childhood cancer may be too young or cognitively impaired to advocate for themselves. Therefore, begin survivorship education by teaching parents to advocate for their children. Parents may in turn teach their child the skills of successful self-advocacy.

“I needed to feel like there was time for me to just talk about the issues, feelings, and struggles we were facing but not expecting to face, following treatment. Now that she was out of immediate danger, I just wanted a chance to talk about what we had been through and what was ahead for us.”

- Arlene, Parent

It should also be noted that parents and patients will have unique perspectives and possibly different goals in mind for the future. Therefore, teaching parents and patients to achieve developmentally appropriate independence may be one of the essential skills taught to both parent and

patient. Professional assistance may be needed to assist with the transitions that occur in the relationship between parent and patient, especially as the patient becomes more independent.

Section 5: Issues in Survivorship

Parents and patients should also be made aware of the unique advocacy opportunities available to each of them. A parent may desire to be much more or less involved in the childhood cancer survivorship arena than the survivor, or vice versa. Therefore, both patient and parent should be equally addressed and given ample and unique opportunities to become involved.

Common Survivorship Issues

An aspect of LTFU clinics that should ideally be separate from the medical aspects of the clinic is built-in time for discussion and processing. The long-term follow-up phase lacks the kind of intensity present during active treatment, but does carry a different sort of intense emotional and physical experience that can many times be eased through discussion and processing.

Life Immediately Beyond Treatment

Survivors should be educated about the possible physical and emotional issues facing them and their families soon after treatment. These issues can be unique and separate from those issues survivors face further out from treatment.

Anxiety: Patients and their families expect and are expected to be thrilled with finishing treatment. However, the thrill of finishing treatment is most often mixed with an intense anxiety when faced with the idea of no longer actively “fighting” the disease. Addressing this issue is an important step in creating a strong foundation for future mental and emotional stability.

Returning to Normalcy: Parents should be educated regarding the frustration, anxiety, and depression felt by patients and members of their family when a realization is made that “back to normal” may not be a possibility and that a “new normal” may need to be established.

Physical Effects: Immediately following treatment, parents should be informed about what to expect for their child in terms of physical condition and ability. At this time, parents should be made aware of immediate side effects of treatment as well as possible long-term effects.

Future Issues: Long-term follow-up clinics should also point out to survivors that physical and psychosocial effects of treatment are sometimes delayed and do not present themselves until many years after treatment. Addressing this possibility up-front, frankly and openly, prevents survivors and their families from feeling they are “weird,” “weak,” or “going crazy” when issues arise at a much later time.

“I hit a huge amount of stress and had a scare that the cancer had come back and suddenly everything that I’d been locking up for the past 4.5 years (since treatment) came out. This goes so much deeper than you realize, and it’s important to have a professional, outside perspective to help you stay on top of your mental/emotional health.”
- Kara, Survivor

Long-Term Psychosocial Issues. *Dealing with a lifetime of psychosocial issues might be both unexpected and overwhelming to parents and survivors. Parents who advocate for their children find themselves dealing with their own emotions, as well as assisting their child in dealing with their own issues. Appropriate support and education on the emotional issues related to survivorship should be made available to parents for their own use as well as for the use of their child. Parents and patients may need to be made aware of the possible issues through discussion, and they should also be given the opportunity to express concerns at each clinic visit. Specific issues that need discussion are as follows:*

Post-Traumatic Stress Disorder: *Survivors and their families should be made aware of the signs and symptoms of PTSD. A discussion of the possibility of this issue may avoid the added stress survivors and/or their families may feel if they are unaware of this issue and simply feel they are “going crazy.”*

Fear of Late Complications: *Some survivors may remember hearing about a potential late complication from their doctor when they were in treatment, or they may know or have heard about other survivors developing physical late effects, such as congestive heart failure or second malignancies, years following treatment. The fear of developing a new health problem may sometimes lead to avoidance of longterm follow-up appointments in the hope that new problems will not be “discovered”. It is important to help survivors understand that participating in long-term follow-up will not cause complications to happen, and that regular long-term follow-up allows these complications to be caught early, when they are most treatable.*

“I didn’t come to the long-term follow-up clinic for a very long time. I thought ‘I am done with that – I’ve paid my dues – I don’t want to know if anything else can go wrong.’ I was really scared that they would find something seriously wrong with me, and that I just couldn’t face having to deal with that, so I thought I would just take my chances. . . . But then, gradually, I began to realize that if I didn’t take charge, the cancer and everything I had gone through was going to take charge of me. Because it was always there, in the back of my mind, and I was always worried about what might happen. So I finally went in for a visit, and now I know the risks that I face. And I actually

feel better knowing that, because now I have a plan to deal with it, and I know the things I can do to keep myself as healthy as possible. And if anything does go wrong, they'll catch it early, and I'll have a better chance of beating it. So, I never miss my appointments anymore."

- Laura,
Survivor

Fear of Recurrence: *Possibly the most universally talked about "issue" facing survivors is a very intense, sometimes debilitating fear of their cancer coming back. Parents and survivors should have the discussion, support, and information available to them at LTFU clinics to address this fear. This is one area in particular where the "voice" of other survivors aids in easing the two-fold anxiety: (1) that the cancer will come back and (2) that you are obsessing about the cancer coming back.*

"I am constantly fighting a battle inside my head. One side of me constantly worrying that I will get sick again, the other side fighting what could become my obsession. It helps me so much to hear that other survivors are feeling the same way. At least I know this is normal."

- Angie, Survivor

Social Relationships: *Having experienced a life-threatening situation at such an early age certainly affects the social relationships of the survivor and the family. Survivors struggle with many questions: How do I tell people I am a cancer survivor? What are people going to think? Why do people not understand me? Will anyone want to date me? Is it okay for me to have sex or be on birth control pills? Will my parents ever let go of me enough to let me be a 'normal' teenager/young adult? These are just a few of the many questions facing survivors as they approach different stages and situations in life. Again, open and frank discussion of these sensitive topics may prevent unnecessary hurt and stress.*

"I can't have kids because of my treatment. When do I tell a girl that? Do I wait until we are really involved, or should I tell her upfront? What woman is going to want to be with a man who can't have kids? I am trusting the right person is out there for me, but it is something I struggle with daily."

- Jon,
Survivor

Self-Esteem/ Self-Confidence Issues: *Depending on the type of treatment they received, survivors may face possible lifelong effects of cancer, such as an amputation or cognitive damage. If the impact of these effects is not addressed in terms of self-esteem, a person's ability to function in particular situations can be adversely affected. Low self-esteem can also severely limit a person's visions and goals. Discussion*

and support of this particular issue is vital in LTFU clinic visits. Learning to advocate for oneself generally increases self-esteem and confidence.

Long-Term Physical Effects of Treatment. Managing the long-term physical effects of treatment is an overwhelming, daunting, and complicated task for most survivors. Without a central location, such as a LTFU clinic, from which to coordinate follow-up, many survivors are left without appropriate followup care. Appropriate information must be given out at each clinic visit to ensure the education of the survivor. Ultimately, the survivor knows his/her own body best. Still she/he must be “armed” with evidence to present to family care practitioners, ER doctors, or others with whom the survivor comes in contact.

“I went to student health for something little. After I rattled off my long medical history, the doctor was afraid to treat me and wanted to order several unnecessary tests. It is very frustrating to know more than the doctors about yourself and have to convince people all the time of what you know is right. Survivors need help coordinating their care.”

- Kara, Survivor

Appropriate information should be given to survivors regarding late effects of treatment and appropriate screening. In addition, LTFU clinic visits should include discussion and teaching regarding potential cognitive changes, the developmental implications of cancer therapy during childhood, how to talk to other healthcare providers about issues related to childhood cancer survivorship, and preparation for the transition to the adult healthcare system.

RECOMMENDATION 3: Improve awareness of late effects and their implications for longterm health among childhood cancer survivors and their families.

Commentary: Inadequate knowledge regarding diagnosis and treatment among childhood cancer survivors has been documented, and many survivors are also unaware of their risk for late effects. Although wellness education and care summaries are provided through many LTFU programs, a recent report from the Childhood Cancer Survivor Study revealed that the likelihood of a survivor undergoing a general physical exam or cancer-related visit within a two-year period decreased substantially as the survivor aged or as the time interval from diagnosis increased, and that only a minority of adult survivors of childhood cancer received risk-based healthcare (Oeffinger et al., 2004). Many survivor programs use multidisciplinary teams to provide education and resources regarding late effects - including psychosocial and wellness issues - using

an array of formats (e.g., booklets, handouts, workshops). However, these programs are often geographically distant from survivors and may not serve patients who are beyond the pediatric age range. (Landier, 2007)

The National Cancer Institute's, *Communication in Cancer Care (PDQ®)* stresses the importance of communication between clinicians and patients:^(NCI, 2008)

Communication between clinicians and patients is a multidimensional concept and involves the content of dialogue, the affective component (i.e., what happens emotionally to the physician and patient during the encounter), and nonverbal behaviors. In oncology, communication skills are a key to achieving the important goals of the clinical encounter.[1]. These goals include establishing trust and rapport, gathering information from the patient and the patient's family, giving bad news and other information about the illness, addressing patient emotions, and eliciting concerns.[2-4] Effective and supportive communication can assist the patient and his or her family in navigating a successful transition to palliative care.[5] Moreover, the need for truly informed consent and the patient's right to health care information and compassionate care create ethical, legal, and humanistic mandates for competency in oncology communication.[6]

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Much effort has been made by government agencies and non-government organizations to educate the clinician and patient/parent on their rights and responsibilities, and the importance of patient education before, during and after cancer treatment.

Complimentary and Alternative Medicine (CAM) Treatment of Cancer

There are Federal resources for providers and patients to educate themselves and research complementary and alternative medicine approaches, including: National Center for Complementary and Alternative Medicine (nccam.nih.gov), journal citations specific to CAM (nccam.nih.gov/camonpubmed/), online continuing education series (nccam.nih.gov/videolectures), Medline Plus (medlineplus.gov), and the NCCAM Clearinghouse which provides information on CAM and NCCAM, including publications and searches of Federal databases of scientific and medical literature (<http://nccam.nih.gov/health/clearinghouse/>).

The National Cancer Institute's National Center for Complementary and Alternative Medicine (NCCAM) is sponsoring a number of clinical trials to study complementary and alternative treatments for cancer. Some of these trials study the effects of complementary approaches used in addition to conventional treatments, while others compare alternative therapies with conventional treatments.

NCCAM provides the document, *Thinking About Complementary & Alternative Medicine: A Guide for People with Cancer; Patient and Family Education.*^(NCCAM, 2005)

The salient points of this document state:

What Is Complementary and Alternative Medicine (CAM)?

CAM is any medical system, practice, or product that is not thought of as standard care. Standard medical care is care that is based on scientific evidence. For cancer, it includes chemotherapy, radiation, biological therapy, and surgery.

Complementary Medicine

- *Complementary medicine is used along with standard medical treatments.*
- *One example is using acupuncture to help with side effects of cancer treatment.*

Alternative Medicine

- *Alternative medicine is used in place of standard medical treatments.*
- *One example is using a special diet to treat cancer instead of a method that a cancer specialist (an oncologist) suggests.*

Talk With Your Doctor Before You Use CAM

Some people with cancer are afraid that their doctor won't understand or approve of the use of CAM. But doctors know that people with cancer want to take an active part in their care. They want the best for their patients and often are willing to work with them. Talk to your doctor to make sure that all aspects of your cancer care work together. This is important because things that seem safe, such as certain foods or pills, may interfere with your cancer treatment.


The prevalence and intensity of CAM research is hindered by issues of ethics. There is little incentive or basis for approval by an Institutional Review Board to undertake randomized, placebo-controlled, double-blind studies using CAM when, as is the case with Hodgkin lymphoma, the standard of care treatment has evidence of good success rates. In many cases, clinical studies using CAM or unsubstantiated therapies will only be approved in cases where the standard of care has failed, or the patient's cancer is refractory. **However, the devastating longterm toxicities and side effects of standard treatment provide ethical impetus for finding a treatment approach that does not present such dangers.**

Summary

The current state of the science for the treatment of Hodgkin lymphoma is blessed with success, and at the same time cursed with devastating longterm toxicities and side effects that have a detrimental impact on the cancer survivor's quality of life. In addition to the known acute side effects of chemotherapy and radiation therapy; the adolescent cancer survivor is faced with documented likely chances of recurrence of the disease, growth and cognitive impairment, inability to have children, and an increased risk of death from heart disease and secondary cancers.


In risk based treatment, the risks of the treatment must be weighed against the possible benefit of the treatment. The Patients' Bill of Rights and principles of medical ethics and informed consent to treat are key to the patient's/parent's understanding of their disease, treatment, and survivorship. Advances in research using complementary and alternative medicine (CAM) are providing new evidence to support the use of CAM as standard of care for cancer treatment – largely because these CAM methodologies present a good chance of success, while avoiding the severe side effects of current treatment methods. The patient/parent must retain the right to explore treatment alternatives, and the medical profession must protect the right of the patient/parent to understand and assess the risks and benefits associated with their disease, prescribed treatment, and options for treatment.

Respectfully submitted,



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Appendix

(Documents are provided as electronic files in attachments to the email that contains this statement (or in an email following, depending on size of files.)