7-26-2011

Vaccinating Daughters against Human Papillomavirus: Comparing Mothers of Childhood Cancer Survivors with Community Controls

Heather Leigh Gamble

To the University Council:

The Dissertation Committee for Heather L. Gamble certifies that this is the final approved version of the following electronic dissertation: "Vaccinating Daughters against Human Papillomavirus: Comparing Mothers of Childhood Cancer Survivors with Community Controls."

_____

Gilbert Parra, Ph.D.
Major Professor

We have read this dissertation and recommend its acceptance:

_____

James Klosky, Ph.D.

_____

Leslie Robinson, Ph.D.

_____

Lynda Sagrestano, Ph.D.

Accepted for the Graduate Council:

_____

Karen D. Weddle-West, Ph.D.
Vice Provost for Graduate Programs

VACCINATING DAUGHTERS AGAINST HUMAN PAPILLOMAVIRUS: COMPARING MOTHERS OF CHILDHOOD CANCER SURVIVORS WITH COMMUNITY CONTROLS

by

Heather Leigh Gamble

A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

Major: Psychology

The University of Memphis

August 2011

ACKNOWLEDGMENTS

It is a pleasure to thank those who made this dissertation possible. Enormous appreciations to my major professor, Dr. Gilbert Parra, and research advisor, Dr. James Klosky, whose patience and guidance have been vital to the completion of this project. Also, special thanks to my encouraging committee members, Dr. Leslie Robinson and Dr. Lynda Sagrestano, for whom I have great respect. And finally, infinite gratitude to my husband, parents and brother, to my grandparents and closest friends whose consistent support and love sustained me throughout this process.

ABSTRACT

Gamble, Heather Leigh. Ph.D. The University of Memphis. August 2011. Vaccinating Daughters Against Human Papillomavirus: Comparing Mothers of Childhood Cancer Survivors with Community Controls. Major Professor: Gilbert Parra, Ph.D.

Predictors of HPV vaccination intent for daughters were assessed among mothers of female survivors of childhood cancer and a community control sample of mothers. Mothers of female survivors of childhood cancer (N = 153) presenting at St. Jude Children's Research Hospital for After Completion of Therapy Clinic and a control group of mothers of healthy adolescent females (N = 44) completed a questionnaire which included the measurement of demographic and medical information, knowledge of HPV and cervical cancer, self-efficacy, and health beliefs regarding HPV and cervical cancer. Current vaccination rates were examined and significant factors that influence mothers' intent to have their daughter vaccinated against HPV were identified. Results were based on correlations and linear regression analyses. The constructs measured were entered as predictors of vaccination intent. For mothers with vaccine naïve daughters, intent to vaccinate in the future was negatively correlated with daughter's age and perceived barriers, and positively correlated with perceived severity, perceived benefits, and self-efficacy. Four factors and two covariates (group, daughter's age, perceived severity, barriers, benefits, and self-efficacy) accounted for more than 37% of the variance in intent. Daughter's age and perceived benefits demonstrated significant unique effects on intent to vaccinate. Findings of the current study further our understanding of familial decision-making about child and adolescent health through identification of factors influencing HPV vaccination among female survivors of childhood cancer and healthy

controls. Findings will also inform future interventions aimed at increasing HPV vaccination.

TABLE OF CONTENTS

APPENDIXES

Vaccinating Daughters against HPV: Comparing Mothers of Childhood Cancer Survivors with Community Controls

Genital human papillomavirus (HPV) is the most common sexually transmitted infection. Vaccines to prevent HPV infection have been licensed by the U.S. Food and Drug Administration (FDA) for use in females and males. Vaccination rates among females with a history of childhood cancer, a population at higher risk for HPV-related complications, have yet to be documented. Many survivors are at high risk for HPV complications because of the direct and indirect effects of cancer treatment; therefore HPV vaccine uptake is particularly important for females surviving cancer. The Children's Oncology Group's *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancer* (COG LTFU) recommends HPV vaccination for all eligible female childhood cancer survivors. Given that the HPV vaccine was approved for widespread use in females only 5 years ago, and in males only 2 years ago, the extant literature is only beginning to document early rates of HPV vaccination uptake among the general population. In order to facilitate future vaccine uptake it is also important to identify factors that influence intentions to obtain the HPV vaccine. The present study is the first to investigate rates of HPV vaccination among adolescent female cancer survivors and to compare families of adolescents treated for cancer to their healthy peers on a number of HPV-related factors. The relations of HPV-related factors, medical and demographic factors in particular, to mothers' intent to vaccinate daughters against HPV were also examined.

Genital HPV is the most common sexually transmitted infection (Sauvageau, Duval, Gilca, Lavoie, & Ouakki, 2007; Weinstock, Berman, & Cates, 2004).

Epidemiological studies indicate that approximately 50–70% of sexually active women contract HPV at some point during their lifetime (Mariam, 2005). More specifically, the prevalence of HPV has been estimated to be as high as 39.6% among 14- to 19-year-olds and 49.3% among 20- to 24-year-old sexually active females (Dunne et al., 2007). Human papillomavirus infection rates are highest in younger women and rise sharply soon after the mean age of first sexual activity – between 16 and 17 years for females (Kahn, Rosenthal, Succop, Ho, & Burk, 2002; Winer et al., 2003; Wulf, 2002).

HPV is a double-stranded DNA virus that infects squamous epithelia, and infection with oncogenic HPV strains is a contributing factor to different types of anogenital cancer including cervical, vaginal, vulvar, penile, and anal cancers, as well as head and neck cancers. Of the over 100 identified types of HPV, approximately 40 strains affect the genital tract (Munoz et al., 2003). Screening for cervical cancer is performed by Papanicolaou (Pap) testing to identify abnormal cells in the cervix that may lead to cancer. Some HPV infections may be asymptomatic and most women with HPV infections have normal Pap test results, as the infection clears without causing any kind of abnormality (National Cancer Institute, 2007). However, all HPV strains have the potential to cause abnormal results, indicating development of precancerous cells in the cervix (American College of Obstetricians and Gynecologists, 2004). Although most HPV infections will resolve on their own, persistent human papillomavirus infection is a necessary cause of cervical cancer (Ault, 2007). Although HPV occurs most often in sexually active adolescents and women aged 15 to 24 years, cervical cancer diagnosis most often occurs in women over the age of 40, with median age at diagnosis for all cervical cancer patients being 47 to 48 years (Ries et al., 2006; Watson et al., 2008).

Recent efforts to promote cancer prevention and control practices have led to the development of vaccines against HPV, which are currently available and have been demonstrated to be clinically effective (CDC, 2007; Harper et al., 2006; Koutsky & Harper, 2006). In June of 2006, the U. S. FDA approved Gardasil, a quadrivalent vaccine that protects young women from the 4 types of HPV (HPV types 6, 11, 16, and 18) which account for 70% of cervical cancers and 90% of genital warts cases (Villa et al., 2005). In clinical trials, Gardasil has demonstrated nearly 100% efficacy in protecting females against these 4 HPV types (Villa, 2007; Villa et al., 2006). Additionally, the vaccine is generally well tolerated and highly immunogenic, indicating good safety and immunogenicity (Reisinger et al., 2007). In October of 2009, the FDA licensed Cervarix, a bivalent vaccination against HPV types 16 and 18, and was approved for use in females aged 10 through 25 years (Centers for Disease Control and Prevention, 2010a).

The FDA approved the Gardasil vaccine for girls and women between the ages of 9 and 26 years (FDA, 2006b). Because it is recommended that girls receive the series of injections prior to the onset of sexual activity, universal HPV vaccination is recommended by the Advisory Committee on Immunization Practices (ACIP) for adolescent females aged 11- and 12-years-old; the series of three injections is administered over six months and can be started as young as 9 years of age (CDC, 2007). It is also recommended that young women aged 13 to 26 years who have yet to be vaccinated or complete the 3-shot vaccine series still receive the HPV immunization - known as a catch-up vaccination (CDC, 2007). In the fall of 2009, the FDA also licensed the HPV vaccine for use in males between the ages of 9 and 26 years for the prevention of genital warts (FDA, 2010).

The projected benefits of mass HPV immunization are considerable. The American Cancer Society estimates a possible reduction of cervical cancer risk by 70% or more with the vaccine's use over many decades (Saslow et al., 2007). Such a decline in cervical cancer rates will depend on the number of carcinogenic HPV types targeted by the prophylactic vaccine, durability of protection, degree of vaccination coverage of the at-risk population, and whether the medical community and the public continue to follow recommended screening guidelines (Saslow et al., 2007). Furthermore, published studies have estimated the HPV vaccine to demonstrate significant cost-effectiveness (Huang, 2008; Markowitz et al., 2007; Zimet, Shew, & Kahn, 2008). Therefore, promotion of HPV vaccine uptake is critical.

As the human papillomavirus vaccine has been widely available for only five years, sparse literature exists indicating precisely how many females have received (and completed) the immunization series to date. Medical audits conducted one year post FDA approval of the vaccine found that as of early 2008, only 10% of age eligible girls and young women initiated and only 2% had completed the three-dose series (Sheinfeld Gorin, Franco, & Westhoff, 2008). Numerous clinical trials were conducted prior to Gardasil's approval by the U.S. FDA, and at least 21,000 females were vaccinated over four clinical trials (FDA, 2006a). In a national study conducted by the Centers for Disease Control and Prevention (CDC) to estimate vaccination coverage among adolescents, it was recently reported that 44.3% of adolescents aged 13-17 years received at least one dose of the HPV vaccine series and 26.7% completed the 3-dose vaccine in 2009 (Centers for Disease Control and Prevention, 2010b).

Certain populations are at an increased risk for HPV infection and HPV-related health problems. For example, the prevalence of cervical squamous intraepithelial lesions and the incidence of cervical cancer caused by HPV are higher among women who are human immunodeficiency virus (HIV)-positive (Palefsky, 2007, 2009). Similarly, patients who receive immunosuppressive therapy following organ transplantation have shown increased anal intra-epithelial neoplsia due to HPV-infection (Roka et al., 2004). Due to the direct and indirect effects of cancer treatment and its suppression of immune functioning, female survivors of childhood cancers are also at increased risk for HPV-related health consequences (Klosky et al., 2009). Additional research is needed to understand the current prevalence of HPV vaccination, particularly among populations at high risk for HPV infection and related complications.

Female Survivors of Childhood Cancer

The HPV vaccine is an important advancement for public health with specific benefits relating to the primary prevention of cervical and other cancers. Research must focus on understanding the factors which relate to HPV vaccination particularly among high-risk populations such as groups who are immunocompromised or are less likely to engage in Pap screening as recommended. Female survivors of bone marrow transplantation as part of cancer treatment are at significantly increased risk for abnormal Pap test results, precancerous markers of cervical cancer known as cervical dysplasia, and second cancers including cervical cancer (Klosky et al., 2009). As a result, study of HPV vaccination intent and completion is needed among female survivors of childhood cancer, who are at greater risk for HPV-related complication due to altered immunity post cancer treatment, particularly for those who have experienced bone marrow transplant.

Initiation of the immune response to HPV infection is largely orchestrated by epithelial cells within the lower genital tract. Via pathogen recognition, expression of antimicrobial mediators, and production of cytokines and chemokines that direct the immune response, genital tract epithelial cells play a key role in immunity to HPV (Quayle, 2002). Cancer patients treated with therapies toxic to mucosal surfaces, such as anthracyclines and radiotherapy, may be more prone to HPV infection simply on the basis of impaired genital tract epithelial cell function. Survivors with chronic graft-versus-host disease that involves the genital tract mucosa may also have impaired epithelial cell function. When considering the potential for an underlying genetic predisposition to malignancy in patients already treated for cancer during childhood, one can argue it is essential to study factors relating to intent to receive and completion of the HPV vaccine in this group.

In a study examining second malignancies among 3,182 children who underwent allogeneic bone marrow transplant as part of treatment for acute lymphoblastic leukemia, researchers reported that the estimated cumulative risk for a new solid cancer was 11% by 15 years after transplant, which represented a 34-fold increased risk compared with expected population-based rates (Socie et al., 2000). Sasadeusz and colleagues (2001) documented a significantly higher rate of cervical cytological abnormalities in recipients of both allogeneic and autologous transplants when compared to the general population. The proportion of abnormal Pap smears is typically 3% to 6% among healthy women; however, for women 3 years post bone marrow transplantation, disproportionate rates of abnormal Pap smears ranged from 14% to 54% and from 4% to 33% for allogeneic and autologous transplant recipients, respectively (Sasadeusz et al., 2001).

In a recent study of 38 females followed 7 years after allogeneic transplant, 43% had abnormal Pap cytology smear findings, with 20% experiencing HPV-related high-grade (and 14% experiencing low-grade) squamous intraepithelial lesions (Savani et al., 2008). Furthermore, those women experiencing chronic GVHD post-transplant that required prolonged systematic immunosuppressive therapy for >3 years were at the highest risk for dysplasia and more aggressive abnormalities of the cervix. Finally, a retrospective study examining the occurrence of new solid cancers among 2,129 patients who underwent bone marrow transplantation between 1976 and 1998 reported that the cumulative probability for developing a solid cancer was nearly 15% at 15 years after bone marrow transplant (Bhatia et al., 2001). More specifically, transplant recipients had a 13-fold increased risk for the development of cervical cancer compared with expected population-based rates.

These findings may be explained by immunosuppression that permits persistent HPV replication that otherwise would not occur. Indeed, there is evidence in other settings such as renal transplantation that immunosuppression is associated with a greater incidence of HPV infection and cervical intraepithelial neoplasia than is seen in age- and parity-matched controls (Seshadri, George, Vasudevan, & Krishna, 2001). Women with Hodgkin lymphoma and those treated with pelvic irradiation are also more susceptible to HPV-related complications, likely due to compromised immune functioning (Klosky et al., 2009). In the largest study of HPV infection among women with Hodgkin lymphoma performed to date, a retrospective review of medical charts of 666 patients consecutively treated at The University of Texas M. D. Anderson Cancer Center between 1963 and 1982 revealed that among the 85 study participants, 46% had HPV infection and related

neoplasia of the cervix or anogenital region (Katz, Veanattukalathil, & Weiss, 1987). Additionally, women treated with pelvic irradiation are significantly more likely to experience HPV-related cervical and vaginal dysplasia and carcinomas of the genital tract, which are attributed to recurrence of original malignancy, mutation of cervicovaginal mucosa cells due to radiation exposure, natural HPV dysplastic processes, or a combination of these mechanisms driven by treatment-induced immunosuppression (Fujimura, Ostrow, & Okagaki, 1991).

In sum, there is mounting evidence of increased risk for HPV-related health consequences for females with history of Hodgkin lymphoma, those treated with pelvic irradiation, and those who have undergone bone marrow transplant. As of yet, it is unclear is this added risk will extend to all forms of childhood cancers or all methods of childhood cancer treatment. It is nonetheless important to address the potential protective health benefits HPV vaccination may offer adolescent female childhood cancer survivors who are at increased risk for HPV-related complications.

In addition to treatment-related predisposition, survivors of childhood cancer also engage in behaviors which increase their risk for HPV infection and complications. For example, survivors of childhood cancer are also at increased risk for infertility, and female survivors who perceive themselves to be infertile may be at increased risk to engage in riskier sexual behaviors including lack of birth control use (Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004). Relatedly, health care screening utilization in survivorship has been an issue among female survivors of childhood cancer as they are less likely than their healthy siblings to have had a recent Pap smear (Hudson et al., 2003;

Oeffinger et al., 2004; Yeazel et al., 2004), with Hispanic survivors having been the least likely to have had a Pap test within the last 3 years (Castellino et al., 2005).

Cognitively speaking, inattention and hyperactivity are commonly reported late effects of childhood cancer treatment. These symptoms have been associated with increased risky sexual behaviors, such as engagement in casual sex and infrequent condom use, among young adults diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) as children (Flory, Molina, Pelham, Gnagy, & Smith, 2006). In a comparison of adolescents and young adults that had been diagnosed with ADHD as children within a community control group, a greater percentage of the hyperactive group had become parents at follow-up and had been treated for a sexually transmitted disease (Barkley, Fischer, Smallish, & Fletcher, 2006). Engagement in risky sexual behaviors could place survivors with problems with inattention/hyperactivity at greater risk for contracting sexually transmitted infections such as HPV.

Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers have been developed by the Children's Oncology Group (2006) and serve as the gold standard in regard to the management of late effects that may arise due to treatment of pediatric cancer. The recommendations, resulting from thorough literature review and collective multidisciplinary clinical experience, are intended to increase awareness of potential late effects and to standardize as well as improve follow-up care for survivors of childhood cancers. In March of 2006, the second version of these guidelines was published based on updated research findings related to late-effects of pediatric cancer treatment, and a third version of these guidelines was released in October 2008. Included in these guidelines are recommendations for health counseling regarding

the benefits of HPV vaccination for female patients who have survived childhood cancer. The endorsement of the HPV vaccine by the panel generating the COG LTFU Guidelines is a testament to the importance of the HPV vaccine in this relatively high-risk population. Indeed, medical, behavioral and cognitive late effects of cancer treatment place survivors of childhood cancer at increased risk for HPV-related complications, and identifying factors which influence familial decisions to obtain HPV vaccination is warranted in this population. The present study examined the predictive influence of the factors discussed below for intent to have daughters vaccinated among mothers of understudied target populations by comparing at-risk youth with healthy peers. Such comparisons will address differences in predicative factors for intent to vaccinate and will assist in tailoring future interventions to promote HPV vaccinations among high-risk populations.

Influential Factors on Intent to Vaccinate Daughters for HPV

To facilitate future vaccine uptake it is important to identify factors that influence intentions to obtain the HPV vaccine. Immunization against HPV is likely a familial decision-making process. Parents/caregivers often determine whether to vaccinate their daughters and therefore are salient to the vaccine's utilization. Parents are their children's and adolescents' primary means for obtaining health care, as states conventionally recognize the right of caregivers to determine health care decisions on their children's behalf (Boonstra & Nash, 2000).

Because the vaccine for HPV is relatively new (approved for use among females by the FDA June, 2006), little is known about the complexity of familial and other factors which may affect decision-making regarding the HPV vaccination, particularly among

high risk populations which may be at relatively increased risk for HPV-related complication. Vaccination rates among high risk populations are unknown, and there is a need for greater understanding of the complicated decision-making process for families to vaccinate daughters against HPV, as it not only involves issues related to vaccination but also adolescent sexual behavior. In a recently developed conceptual model (Gamble, Klosky, Parra, & Randolph, 2009), guided by the Health Belief Model, Theory of Planned Behavior, and Social Learning Theory, it was proposed that the following variables may have direct predictive influence on mothers' intent to have daughters vaccinated for HPV: Health Belief Factors, Cues to Action including Sexual Communication with Daughters, Knowledge of HPV-Related Health Risks, Socio-Environmental Factors, Self-Efficacy, and Medical and Demographic Factors. Appendix A illustrates the conceptual framework for understanding familial decision-making as it relates to HPV vaccination. Given the large number of factors that may contribute to intent to vaccinate daughter's for HPV, and the lack of research pertaining to HPV immunization among cancer survivors, the focus of this paper has been narrowed to include medical and demographic factors, health beliefs, self-efficacy, and knowledge of HPV and cervical cancer. Focusing on these more basic yet relevant factors is a starting point to identify those most influential in predicting HPV vaccination among families whose daughters have survived childhood cancers. Future studies will continue to further examine additional constructs within the conceptual model.

Completion of HPV immunization is first influenced by intentions to receive the HPV vaccine. The conceptual model helps to identify significant predicting factors that influence mothers' intent to have their daughters vaccinated for HPV. The Theory of

Planned Behavior proposes that an individual's attitudes toward a behavior, perceptions of the beliefs of significant others (norms), and perceived control over the behavior influences his or her behavioral intent, which in turn drives engagement in the actual behavior (Ajzen, 1991). Such a theory assumes behavioral intention is the most significant determinant of engaging in a behavior, with intent initially influenced by personal evaluation of a behavior and beliefs about whether important people would approve or disapprove of the behavior (Rimer & Glanz, 2005). In other words, multiple factors influence HPV vaccine intent, which subsequently predicts HPV vaccine completion. Numerous factors likely fall between HPV vaccine intent and subsequent completion of vaccination. However, this exploratory study will focus exclusively on factors predictive of mothers' intent to have daughters vaccinated for HPV, rather than those which influence actual immunization implementation. In order to promote the vaccine among those who have yet to initiate HPV immunization, it is important to assess future intent to vaccinate and identify factors that predict intentions of getting the vaccine.

Health Beliefs Factors

The Health Belief Model, previously applied to a number of health behaviors including vaccination and contraceptive practices, proposes four primary constructs that aid in accounting for people's readiness to act (Rimer & Glanz, 2005). They are perceived susceptibility, perceived severity, perceived barriers, and perceived benefits (Glanz, Rimer, & Lewis, 2002). Two additional constructs, cues to action and self-efficacy, have been added in recent years; however, there has been less empirical support in studying these last two factors as part of the Health Belief Model. Within the

conceptual model, the health belief factors are largely made up of components from the Health Belief Model, as these constructs have previously been demonstrated to influence HPV vaccine acceptance (Brabin, Roberts, Farzaneh, & Kitchener, 2006; Gerend, Lee, & Shepherd, 2007), but may also include may include *attitudes and beliefs* held by mothers regarding immunization. *Perceived susceptibility* is one's subjective perception of the risk of contracting a health condition, such as HPV or cervical cancer. For example, how likely is my daughter to become infected with HPV? Denial of any need to vaccinate daughters has characterized parental resistance to vaccinating daughters (Constantine & Jerman, 2007). *Perceived severity* is one's opinion of how serious a condition and its consequences are. For example, parents may question the severity of treatment for their daughters' HPV-related conditions, or social consequences such as disclosure of HPV infection to sexual partners, health care professionals, and insurance companies. Applied to the HPV vaccine, *perceived benefits* would include reducing a daughter's risks of contracting HPV thus reducing her chance of developing cervical cancer. *Perceived barriers* are opinions on the tangible, as well as psychological, costs of obtaining HPV vaccination for one's daughter including pain associated with HPV injections, financial costs, perceptions of side-effects and unknown risks. Belief that HPV immunization would promote earlier initiation of coitus and encourage sexual activity has characterized the opposition that some parents have to the vaccination (Brabin et al., 2006).

Knowledge of HPV-Related Health Risks

Knowledge of HPV and its link to cervical cancer likely affects intention to vaccinate. Mothers are more knowledgeable of HPV health risks when they understand HPV transmission, are educated on the link between HPV and cervical cancer, and are

familiar with HPV treatment and vaccination safety and efficacy. Low levels of HPV knowledge have been observed among parents and adolescents, as few have heard of HPV or a vaccine. Prior to HPV vaccination approval, Brabin et al. (2006) surveyed parents regarding potential acceptance of such a vaccination. Findings indicate that few parents knew of HPV or a vaccine for HPV, however 81% reported they would agree to have their child vaccinated. Parents with higher knowledge levels report greater acceptance of the vaccine, whereas lack of disease-specific knowledge and questions about vaccine safety have been linked to rejection of vaccination against STIs.

Self-Efficacy

Another proposed influence on HPV vaccine intentions occurs by means of self-efficacy. As it relates to the Health Belief Model, self-efficacy is one's confidence in her ability to successfully take action. Self-efficacy is not only a component of the Health Belief Model but also a construct of Bandura's Social Cognitive Theory, a theory which may be relevant in health behavior (as cited in Glanz et al., 2002). Self-efficacy in Social Cognitive Theory is "the person's confidence in performing a particular behavior and in overcoming barriers to that behavior" (Glanz et al., 2002, p. 169). Little empirical research has been conducted to examine self-efficacy factors linked to HPV vaccination. Proposed examples of mothers' self-efficacy are perceived ability to get daughter to physician clinic, perceived ability to effectively communicate with daughters about sexual topics and successfully negotiate with teens regarding completion of the 3-shot vaccination series. An individual can engage in behavioral changes, even in the face of obstacles, when she feels a sense of personal agency (Rimer & Glanz, 2005).

Medical and Demographic Factors

Parent and adolescent medical and demographic factors are directly related to intention to seek HPV vaccination. Medical factors represent parent and adolescent health histories. Demographic factors are population characteristics. Prior research has examined the association of *age, gender, ethnicity, parent education, marital status, and income* with acceptance of HPV vaccination. Previous studies have found no association between vaccine acceptance and parent socio-demographic factors including ethnicity, age, and religion (Brabin et al., 2006). Also, while no significant effects for parent age or gender emerge, Hispanic parents were more likely to endorse vaccination whereas Asian-American and African-American parents were less likely to do so (Constantine & Jerman, 2007). Proposed medical influences on acceptance of HPV vaccination may include *history of cancer, abnormal Pap test results and history of Pap screening, history of STI testing, and childhood immunization records*. Among mothers from a community health clinic, correlates of HPV immunization acceptability included history of HIV testing (Gerend et al., 2007). Slomovitz et al. (2006) report that a history of abnormal Pap tests has not been shown to be associated with women's acceptance of the HPV vaccine for either themselves or their children. However, mother's willingness to vaccinate offspring against HPV was associated with whether her child had received all previously recommended immunizations. Evaluating the predictive influence of such demographic and medical characteristics on vaccination intent was important for the current study, as these factors have yet to be examined among populations at high risk for HPV-related health risks.

Limitations exist within the literature at this time. Most studies have surveyed parents, adolescents, and physicians regarding attitudes about HPV vaccine acceptance, yet little is known about intent for getting the vaccine and actual vaccination rates. There is a lack of application of theory to determine health factors from a range of domains simultaneously influencing familial decision-making regarding HPV immunization. Finally, research has yet to examine HPV vaccination issues among those at high risk for HPV-related complication, such as immunocompromised persons and female survivors of childhood cancer, in particular.

Present Study

Study Aims

The purpose of the present study was to examine the influence of HPV-related factors on mothers' intent to vaccinate daughters against HPV. This study is unique in that it targeted a population at higher risk for HPV-related complications (i.e., daughters with a history of childhood cancer) as well as a control group (i.e., healthy daughters). The present study furthers current understanding of familial decision-making about child and adolescent health through identification of factors influencing HPV vaccination among families. This is the first study to compare families of adolescents treated for cancer to their healthy peers on a number of HPV-related factors, which has implications for tailoring interventions based on medical risk factors.

Aim 1 of the present study was to examine current HPV vaccination rates among families with preadolescent/adolescent females. Because little is known about HPV vaccination rates among female survivors of childhood cancer, comparisons were made between cancer and controls groups with regard to current vaccination rates as well as

intent to vaccinate. Aim 2 was to compare hypothesized influences on intentions to obtain the HPV vaccine (i.e., medical and demographic factors, cervical cancer/HPV knowledge, health beliefs, and self-efficacy) between cancer and control groups.

Aim 3 was to assess the relations of medical and demographic factors (i.e., maternal age, ethnicity, marital status, education, income, Pap history, STI history, daughter's age, daughter's immunization history, and physician recommendation for HPV vaccination), cervical cancer/HPV knowledge (i.e., how HPV is transmitted and risk factors for infection), health beliefs (i.e., perceived susceptibility, severity, barriers, benefits, and beliefs about decisions), and self-efficacy (i.e., mothers' ability to talk with physician, get daughter to medical clinic, complete the 3-shot series) to HPV vaccination intent among mothers with preadolescent/adolescent daughters. As this study is exploratory in nature and this area has yet to be studied in this high risk population, no clear expectations are made with regard to whether mothers of cancer survivors will vaccinate daughters at higher or lower rates than the healthy population, whether groups will differ on hypothesized predictors of intent, or which factors will predict intent to vaccinate daughters against HPV in the future.

Method

Participants

The sample for the present study was comprised of mothers/female caregivers whose daughters are active patients in the After Completion of Therapy Clinic (i.e., ACT survivorship clinic) at St. Jude Children's Research Hospital (SJCRH). The study sample was also comprised of mothers/female caregivers of daughters without a history of childhood cancer (i.e., community controls). To be accepted into the ACT clinic, patients

must have had a previous diagnosis of malignancy, be 5 years post diagnosis, and completed cancer therapy at least 2 years previously. Participants for the present study (a) were mothers/female primary caregivers of active patients who participate in the After Completion of Therapy (ACT) clinic at SJCRH, (b) had daughters aged 9 to 17 years of age at time of study enrollment, (c) were proficient in reading and writing English, (d) were cognitively intact such that the study questionnaire could be understood and completed, and (e) completed signed informed consent consistent with institutional guidelines.

In order to obtain a control sample demographically most like the cancer group based on daughter's age and mother's SES and race, each mother recruited for participation at SJCRH was asked to provide contact information for up to 5 acquaintances, following completion of the study questionnaire. The acquaintances were also mothers with daughters between the ages of 9 and 17 years-of-age, so that the primary distinguishing feature of mothers in the community control group and mothers in the cancer group was presence/nonpresence of daughter's cancer history. Obtaining a control group using acquaintance methodology is likely to provide a control sample demographically most like the cancer group, matched on daughter's age and mother's SES and ethnicity.

Participants in the community control sample (a) were mothers/female primary caregivers acquainted with participating mothers from SJCRH, (b) had daughters aged 9 to 17 years of age at time of study enrollment, (c) were proficient in reading and writing English, (d) were cognitively intact such that the study questionnaire could be understood

and completed, and (e) completed informed consent consistent with institutional review board guidelines.

Participants included 197 female primary caregivers of daughters, and the majority (78.7%) of the sample mothers were Caucasian. As most female primary caregivers (93.4%) reported being the biological mother of the index daughter, for simplicity's sake, female primary caregivers are referred to as parents or mothers hereafter. Mothers' mean age was 41.75 years (*SD* = 6.96). Daughters' mean age was 13.34 years (*SD* = 2.68). The sample was composed of 153 mothers of childhood cancer survivors and 44 control mothers of healthy daughters. Mothers of survivors of childhood cancer ranged in age from 27 to 62 years (*M* = 41.65, *SD* = 7.04), and is considered generally representative of the pediatric cancer population in the US. Daughters with a history of childhood cancer ranged in age from 9 to 17 years (*M* = 13.33, *SD* = 2.71). The survivor sample consisted of 75.8% whites and 18.3% African Americans. Mothers of healthy control daughters ranged in age from 29 to 56 (*M* = 42.09, *SD* = 6.71). Daughters without a history of childhood cancer ranged in age from 9 to 17 years (*M* = 13.36, *SD* = 2.62). The control sample consisted of 88.6% whites and 2.3% African Americans.

Procedures

St. Jude cancer group study procedures. The present study did not involve any therapeutic or intervention component, but relied solely on the use of the self-report questionnaires. Mothers of patients from SJCRH were recruited from the ACT clinic. Mothers meeting study criteria were recruited consecutively within the time constraints of the availability of staff. That is, for every opportunity where there was staff available for recruitment, the researchers attempted to enroll the first available mother meeting

eligibility criteria, in an effort to reduce selection bias that would favor enrollment of patients' mothers known to study staff or recommended by other staff. Eligible SJCRH mothers who agreed to participate were asked to sign a consent form following an explanation of the institutional review board-approved study. All participants were informed that their responses will remain confidential. Mothers who agreed to participate were asked to complete a battery of paper and pencil questionnaires that assessed factors predictive of HPV vaccination intent for their daughter as described below. The research instrument consisted of a self-administered questionnaire inquiring on demographic and medical information, knowledge of HPV and related health risks, health beliefs about HPV and vaccination, cues to action, socio-environmental influences, self-efficacy, sexual communication with their daughter, and vaccination intent for their daughter. The self-administered questionnaire (see Appendix H) was developed based on a review of the literature and previous research experience (Brabin et al., 2006; CDC, 2007; Constantine & Jerman, 2007; Davis, Dickman, Ferris, & Dias, 2004; Dempsey, Zimet, Davis, & Koutsky, 2006; Gerend et al., 2007; Kahn et al., 2008; Lazcano-Ponce et al., 2001; Rosenthal et al., 2008). These measures required approximately 30 minutes to complete. One-hundred eighty-five eligible ACT mothers were invited to participate. Of those 185, 178 (96%) consented to participate in the study and 153 (86%) completed study questionnaires were returned. Seven eligible mothers declined to participate, stating that they were not interested in the study. Please see Appendix B.

Community control group study procedures. Efforts were made to collect a control sample of mothers of healthy preadolescent/adolescent females demographically most like that of the families of patients in the ACT clinic. Mothers in the acquaintance

sample meeting eligibility criteria were invited to participate in the study. Acquaintances were contacted regarding participation in the study and the study was presented to the acquaintance control mother. Once the participant provided verbal informed consent for study participation, the same paper and pencil questionnaires that assess factors predictive of HPV vaccination intent for their daughter as mentioned above for the SJCRH parent group (see Appendix H), were sent via postal mail or via a link in a secured email, which ever was preferred. All participants were informed that their responses will remain confidential. One-hundred twenty-eight eligible control mothers were invited to participate. Of those 128, 72 (56%) consented to participate in the study and 44 (61%) completed study questionnaires. Two eligible mothers declined to participate, stating that they either did not have time to complete the study measure or were not interested in participating. Please see Appendix C.

Both SJCRH and control participants were told that they would complete a survey about cervical cancer vaccination and their daughter's health and that participation was voluntary. Mothers were asked to answer all questions about their daughter with a history of childhood cancer, or for the control group mothers, their daughter closest in age to the daughter from the referring St. Jude family. A number of procedures were employed to assure participants that their responses will remain confidential. Identification numbers rather than participant or patient names were used. After completing the survey, participants were instructed to seal it in an unmarked envelope. For SJCRH patient mothers, efforts to ensure confidentiality were made including the use of study code numbers rather than names, and the provision that information disclosed by mothers about sexual behavior would not be shared with medical staff or included in the

daughter's medical chart. All data was stored on a password protected computer and data forms were kept in a locked file cabinet. Access to the data was limited to study staff. Following the completion of the study questionnaire, all mothers received a brief information sheet outlining the health risks of HPV infection and utility of HPV vaccination (see Appendix J). The study was approved by both The University of Memphis and St. Jude Children's Research Hospital Institutional Review Boards (see Appendix K).

Measures

Appendix D summarizes the variables studied, where the items are located in the questionnaire, and the source which guided development of the questionnaire items.

Current Vaccination Status. Daughters' HPV vaccination status was determined by one 4-point item. The item read "Has your daughter received the HPV vaccine (Gardasil or Cervarix)? Mark only one answer." In terms of responses, the maternal participant marked 1 of 4 options with the stem, "My daughter has received…" (a) 0 of the three shot series (has NOT received any of the HPV vaccine), (b) 1 of the three shot series, (c) 2 of the three shot series, and (d) 3 of the three shot series (has completed the HPV vaccine). Responses were dichotomized to reflect those who have and have not initiated HPV vaccination. HPV vaccination status for mothers was also determined by one 3-point item. Responses were 1 (*yes*), 2 (*no*), and 3 (*not sure*).

Vaccination Intent (Primary Dependent Variable). For those mothers who marked the letter "A" on the above item indicating that their daughter has received 0 of the 3 shot series (i.e., has NOT received any of the HPV vaccine), they were asked to complete 4 items assessing intent to vaccinate daughter for HPV. The maternal participant was asked

to answer 4 items with the stem, "How likely is it that you will have your daughter…" (a) start the HPV vaccine within the next month, (b) start the HPV vaccine within the next 6 months, (c) start the HPV vaccine within the next 12 months, and (d) vaccinated for HPV in the future? Each item allowed for responses which ranged from Definitely Will Not (0) to Definitely Will (6). Items regarding vaccination intent were adapted from questions used in previous research (Constantine & Jerman, 2007). Due to missing data on some or all of the 4 intent items, only the final intent item (item "D" above) was used to assess for any future intent to vaccinate daughters, generating scores which ranged from 0 – 6, with higher scores indicating greater likelihood to vaccinate their daughter in the future. This continuous variable of HPV vaccination intent was used as the primary dependent variable for this study, and was only considered for those who indicated that their daughters are naive to HPV vaccination.

Medical Care and Demographic Factors. All mothers/female primary caregivers were asked to provide information on their age, race/ethnicity, marital status, education level, and annual household income. Maternal marital status was categorized as "married," "widowed/divorced/separated," or "other." Maternal education level was measured as a continuous variable by seven items ranging from grade school to graduate degree. Additionally, annual household income for each participant was assessed using sixteen items ranging from $0-$9,999 to more than $150,000. Items requesting demographic background were adapted from previous research instruments (Brabin et al., 2006; Constantine & Jerman, 2007; Dempsey et al., 2006).

Maternal medical background included mothers' history of Pap testing and STI, including HPV infection and cervical cancer. One item assessed whether daughters have

received all recommended childhood vaccinations. A final item assessed whether or not daughter's doctor has recommended that she receive the HPV vaccine. Responses for all medical background items were 0 (*no*) and1 (*yes*). Items regarding mothers' history of STI, and abnormal Pap test were adapted from previous self-report questionnaires (Rosenthal et al., 2008).

General Knowledge of HPV and Related Risk Factors. Knowledge of HPV, cervical cancer, and HPV vaccination was measured using items adapted from previous work by Brabin and colleagues (2006) and from the CDC's website for HPV vaccination information (CDC, 2007). Ten multiple choice items were used to assess mothers' knowledge of HPV-related health risks. Participants were provided with questions and asked to select the correct answer from four possible answer choices. Participants scored 1 or 0 for each response and the number of correct answers was summed to create a knowledge score for each participant. Scores ranged from 0-10 with higher scores representing more accurate responses and greater levels of HPV-related knowledge.

Health Beliefs. The four constructs within the Health Belief Model that were examined included perceived susceptibility to HPV infection, severity of HPV infection, barriers to HPV vaccination, and benefits to vaccination. Mothers' perception of their daughter's susceptibility to HPV-related health risks compared to other girls her age was measured by summing five 5-point items, scored 1 (*much less likely*) – 5 (*much more likely*), (e.g., "Compared to other girls her age, how likely is your daughter to have an abnormal Pap test?"). Scores may range from 5-25 with higher scores indicating greater perceived susceptibility ($\alpha = .94$). Mothers' perception of the severity of HPV and related health risks for their daughters was measured by summing eight 5-point items, scored 1

(*strongly disagree*) – 5 (*strongly agree*), (e.g., "Infection with HPV can lead to a serious illness."). Scores may range from 8-40 with higher scores indicating greater perceived severity (α = .86). Perceived barriers to vaccination was measured by summing twelve 5-point items, scored 1 (*strongly disagree*) – 5 (*strongly agree*), with one item reverse scored. An example item stated, "It would be hard for me to find the time to get my daughter vaccinated for HPV." Scores may range from 12-60 with higher scores indicating greater perceived barriers (α = .78). Perceived benefits of vaccination was measured by summing seven 5-point items, scored 1 (*strongly disagree*) – 5 (*strongly agree*), with one item reverse scored. An example item stated, "The HPV vaccine would greatly reduce the chance of getting cervical cancer." Scores may range from 7-35 with higher scores indicating greater perceived benefits (α = .82). Items assessing health belief factors were adapted from the HPV Vaccine Health Beliefs Questionnaire (Cox, Cox, Sturm, & Zimet, 2010), a validated instrument designed to measure the maternal health belief constructs of perceived severity, perceived vulnerability, perceived barriers, and perceived benefits/efficacy as it relates to the HPV vaccine. The questionnaire's instructions direct participants to respond to items on a Likert-type rating scale which ranges from "Strongly Disagree" to "Strongly Agree." The predictive validity of these health belief factors has been established in their relationships with HPV vaccination acceptability among mothers of girls aged 11-16 (Cox et al., 2010).

Self-Efficacy. Mothers' perceived self-efficacy to have daughters vaccinated for HPV was measured by six 5-point items, scored 1 (*strongly disagree*) – 5 (*strongly agree*). Scores may range from 6-30 with higher scores reflecting greater self-efficacy (α = .89). An example of an item on this scale asked mothers to respond to the following, "I

believe that I could get my daughter to the medical clinic." Items regarding mother's self-efficacy for vaccinating daughter were adapted from a previous research questionnaire (Kahn et al., 2008).

Statistical Analysis

Differences between group means of continuous variables were examined using *t* tests, and distributions of categorical variables were compared using χ^2 analyses. Specifically, separate tests were conducted to compare the cancer group and control group on each proposed influence (i.e., medical and demographic factors, cervical cancer/HPV knowledge, health beliefs, and self-efficacy). Of note, levels of predictor influences are reported for all participants, not just mothers of vaccine naïve daughters. Please refer to Appendix E for an overview of these findings.

To examine the third study aim (i.e., to assess the general predictive influence of medical and demographic factors on HPV vaccination intent), a linear regression analysis was conducted. The dependant variable in the regression was mothers' future intent to have their daughters vaccinated, thus utilizing only data from mothers of vaccine naïve daughters. Of note, only mothers with vaccine naïve daughters and complete data for all predictor variables were included for this analysis ($n = 84$). Zero-order correlations were first used to examine relations between all predictor variables and the outcome (intent to vaccinate daughter for HPV), and only predictor variables that had a significant association with intent ($p \leq .05$) were considered in the regression model. Please refer to Appendix F for an overview of these correlational findings. Each variable that was associated with intent was included in a linear regression analysis to determine independent predictors of HPV vaccination intent. In order to control for developmental

differences as well as group status (i.e., mother of childhood cancer survivor or healthy control), age of daughter and daughters' history of cancer status were entered as covariates. Please refer to Appendix G for an overview of the regression results. Statistical analyses were performed using SPSS version 19.0.

Results

Differences between Cancer and Control Groups

The first set of analyses will address Aim 2, which was to compare differences in hypothesized influences on intentions between cancer and control groups.

Demographic & Medical Factors. Findings indicated that there were differences between cancer and control groups with regard to racial/ethnic background. Specifically, the mothers of cancer survivors group included significantly more minorities than the mothers of healthy controls group, as 9.3% of the control sample and 23.7% of the survivorship sample were comprised of participants of minority ethnic backgrounds. Groups did not differ based on maternal age nor on daughters' age. Groups did not differ significantly based on mothers' marital status. No differences in educational background were found between mothers in the control sample and mothers of cancer survivors.

No differences in annual household income were reported between the control mothers and mothers of cancer survivors. Of note, differences in annual income were found between white and minority mothers, with white mothers reporting higher annual income, $t(181) = -3.62$, $p < .01$.

With regard to maternal medical care, 71.1% ($n = 140$) of mothers reported receiving annual Pap tests (68.6% of survivorship mothers and 79.5% of control mothers), and 41.6% reported having ever had an abnormal Pap smear result (39.2% of

mothers of survivors and 50% of mothers of healthy controls). There was no significant difference in receipt of annual Pap test or abnormal Pap test results between groups. Further, 15.2% of mothers reported ever having a STI, 6.6% endorsed ever having an HPV infection, and 9 mothers (4.6%) reported a personal history of cervical cancer. There was no significant difference in history of STI or HPV infection between groups. No difference was found in maternal history of cervical cancer between groups.

An overwhelming majority of mothers (93.9%) reported that their daughter had received all recommended childhood vaccinations, and only 44.7% of mothers endorsed that their daughter's doctor recommended vaccinating for HPV. There was no significant difference between groups in receipt of childhood vaccinations or physician recommendation of HPV vaccination.

Knowledge of HPV & Health Belief Factors. The sample as a whole was relatively unknowledgeable regarding HPV and HPV-related health risks ($N = 197$, $M = 6.13$, $SD = 1.64$). No significant difference was found between groups on HPV-related knowledge scores. Mothers of cancer survivors reported significantly greater perceived susceptibility to HPV and significantly less perceived severity for HPV and related health risks for their daughters than mothers of healthy control daughters. Mothers of childhood cancer survivors did not endorse greater perceived barriers or benefits to HPV vaccination for their daughters than mothers of healthy daughters. With regard to mothers' self-efficacy to vaccinate daughters, mothers of cancer survivors reported no significant differences in perceived self-efficacy to vaccinate than mother's of healthy control daughters. Appendix E also illustrates these findings.

HPV Vaccination Rates and Intent

The next set of analyses will address Aim 1 of the present study, which was to compare cancer and control groups with regard to current HPV vaccination rates as well as intent to vaccinate in the future.

Vaccination Status. Daughter's vaccination status will be described first for the entire sample of participating mothers, followed by the sample of mothers of childhood cancer survivors, and control mothers. Of all mothers participating in the present study (N = 197), 65.99% (n = 130) reported that their daughter has not received the HPV vaccine series, 32% (n = 63) reported that their daughter had either initiated or completed the HPV vaccine series, and 2.0% (n = 4) of mothers did not answer this item. Of those daughters who initiated vaccination, 27% (n = 17) had received 1 of 3 shots, 14.3% (n = 9) had received 2 of 3 shots, and 58.7% (n = 37) of daughters had received all 3 HPV vaccine shots and completed the vaccine series.

Of all mothers participating in the present study (N = 197), 95.9% (n = 189) reported that they had not received the HPV vaccine personally, 2.0% (n = 4) reported having personally received the HPV vaccine series for themselves, 1.5% (n = 3) reported they were not sure whether or not they have received the vaccine, and 0.5% (n = 1) of mothers did not answer this item.

Of the mothers of daughters with a history of childhood cancer (N = 153), 64.7% (n = 99) reported that their daughter had not received the HPV vaccine series, 32.7% (n = 50) reported that their daughter had either initiated or completed the HPV vaccine series, and 2.6% (n = 4) did not answer this item. Of the survivorship daughters who initiated vaccination, 30% (n = 15) had received 1 of 3 shots, 10% (n = 5) had received 2 of 3

shots, and 60% (n = 30) of survivors have received all 3 HPV vaccine shots and had completed the vaccine series.

Of mothers in the survivor sample (N = 153), 94.8% (n = 145) of mothers reported that they had not received the HPV vaccine personally, 2.6% (n = 4) reported having personally received the HPV vaccine series for themselves, 2.0% (n = 3) reported they were not sure whether or not they had received the vaccine, and 0.7% (n = 1) of mothers did not answer this item.

Additionally, 70.5% (n = 31) of control mothers reported that their daughter had not received the HPV vaccine series, whereas 29.5% (n = 13) reported that their daughter had either initiated or completed the HPV vaccine series. Of the control daughters who initiated vaccination, 15.4% (n = 2) had received 1 of 3 shots, 30.8% (n = 4) had received 2 of 3 shots, and 53.9% (n = 7) of daughters had received all 3 HPV vaccine shots and completed the vaccine series.

Of mothers in the control sample (N = 44), 100% (n = 44) of mothers reported that they have not received the HPV vaccine personally. A chi-square test was conducted to evaluate the difference in daughters' vaccination rate between groups (cancer and control; Aim 1). There was no significant difference in vaccination rate between cancer (33% vaccinated) and control (30% vaccinated) groups. Furthermore, no difference was found in vaccination rates between daughters of Caucasian mothers (29% vaccinated) and daughters of minority mothers (42.5% vaccinated), $\chi^2(1) = 3.26$, $p > .05$.

Intent to Vaccinate. Recall that of the total sample, 65.99% (N = 130) of daughters were not vaccinated for HPV. Future intent to vaccinate daughters for HPV was measured by one item ranging from 'Definitely Will Not' to 'Definitely Will,' with

data collected for 120 of the 130 vaccine naïve daughters. No significant difference was found in future intent to vaccinate for HPV between groups. Appendix E provides an overview of these findings.

Influences on HPV Vaccination Intent

The final set of analyses address Aim 3, which was to assess the relations of medical and demographic factors to future HPV vaccination intent. Paring down the sample to include only mothers with vaccine naïve daughters and complete data for all predictor variables *(n* = 84), zero-order correlations examined relations between all predictor variables and the outcome (intent to vaccinate daughter for HPV). Appendix F provides an overview of these correlational findings.

Future intent to vaccinate was negatively correlated with daughter's age and perceived barriers. Intent to vaccinate was also positively correlated with perceived severity, perceived benefits, and self-efficacy. Linear regression analysis was used to determine significant independent predictors of vaccination intent. Each of the five variables associated with intent (i.e., daughter's age, perceived severity, perceived benefits, perceived barriers, and self-efficacy) was included in the regression analysis, with group status (i.e., mother of childhood cancer survivor or healthy control) and age of daughter entered as covariates, and future intent to vaccinate for HPV as the dependent variable. Analyses revealed that the two covariates and four additional variables accounted for more than 37% of the variance in intent to vaccinate (R^2 = .374). Daughter's age (β = -0.18, $p \leq .05$) and perceived benefits (β = 0.41, $p \leq .01$) demonstrated significant unique effects on intent to vaccinate (see Appendix G).

The author was also interested in examining whether the relations between influences and intent were different for mothers in the cancer and control groups. To investigate this possibility, correlations were examined separately for the cancer and control groups. For mothers of childhood cancer survivors, future intent to vaccinate was negatively correlated with daughter's age (r = -0.33, $p \leq .01$) and barriers (r = -0.33, $p \leq .01$), and positively correlated with perceived susceptibility (r = 0.28, $p \leq .05$) and benefits (r = 0.48, $p \leq .01$). For mothers of healthy control daughters, future intent to vaccinate was positively correlated with perceived benefits to immunization (r = 0.65, $p \leq .01$). In other words, belief that there are advantages to the immunization was related to intent to vaccinate for both groups of mothers. For mothers of cancer survivors, specifically, having a younger daughter, perceiving fewer barriers to vaccination, and belief that their daughter was at increased risk for HPV infection and related consequences were also related to future intent to vaccinate.

To further determine whether group status moderated these relations, additional regression analyses were conducted. Using procedures outlined by Aiken and West (1991) continuous variables correlated with intent were centered, interactions terms were computed, and separate regressions were run for each interaction and relevant main effects. The interactions between group status and daughter's age, perceived susceptibility, perceived barriers, and perceived benefits were not significant.

Discussion

The present study was conducted to address 3 primary aims: (a) to examine current HPV vaccination rates as well as intent to vaccinate among families with preadolescent/adolescent females with and without a history of cancer, (b) to compare

hypothesized influences on vaccination intentions to obtain the HPV vaccine (i.e., medical and demographic factors, cervical cancer/HPV knowledge, health beliefs, and self-efficacy) between cancer and control groups, and (c) to investigate the relations of these factors to HPV vaccination intent among mothers with preadolescent/adolescent daughters.

This study is the first to investigate HPV immunization rates and intentions among families of childhood cancer survivors, a population at high risk for HPV infection and complication, and a control group of healthy peers. It also is one of only a few that tests components of a conceptual model designed to explain HPV vaccine intent. As no prior studies have examined HPV immunization rates among or intent to vaccinate childhood cancer survivors, it is important to note that both the survivor and healthy groups endorsed vaccination completion rates lower than the national average, therefore raising concern that survivors of childhood cancer, and their acquaintances, are not being vaccinated as recommended. Results revealed that daughter's age as well as perceived severity, benefits, barriers, and self-efficacy correlated with vaccine intent. Younger age and perceptions of vaccine benefit were also uniquely associated with future intent to vaccinate. Furthermore, factors which predicted HPV vaccination did not differ for mothers of childhood cancer survivors and mothers of healthy daughters. Each of the primary findings is further discussed below.

Examination of HPV vaccination rates among mothers with and without a child surviving childhood cancer found that only 32% of daughters had either initiated or completed the HPV vaccine series. Nearly 66% of participating mothers had not vaccinated their daughter against HPV. Previous reports by the CDC (2010b) indicated

that 44.3% of adolescents in the U.S. had initiated the 3-dose vaccination series and 26.7% had completed the vaccine in 2009. The present study's finding of only 18.8% of daughters completing the vaccine series is therefore lower than the national average.

Results also indicated no difference in vaccination rate between cancer and control groups, indicating that mothers of childhood cancer survivors and healthy controls vaccinate daughters at similar rates. This finding indicates that immunization recommendations are not being met for the general population, and that *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* are not being followed for female adolescent cancer survivors. Many childhood cancer survivors, particularly those treated with hematopoietic stem cell transplantation or pelvic irradiation and those diagnosed with Hodgkin lymphoma, experience persistent immune compromise, and impaired immune function appears to be responsible for increased rates of cervical and oral dysplasia (Klosky et al., 2009). As survivors are at increased risk for HPV infection and related adverse health effects, efforts to improve HPV vaccination in this population is warranted.

One possible explanation for the relatively low vaccination rate in this study is that a majority of the study sample was comprised of mothers of adolescent cancer survivors whose daughters receive a sizable portion of their medical care from the study's recruitment facility. As of yet, this medical setting does not offer HPV vaccination; therefore, mothers would have had to have independently pursued vaccination for their daughters in medical settings other than the recruitment facility – a potential barrier to vaccination. Furthermore, if childhood cancer survivors receive additional medical care from community providers who are aware of the COG LTFU immunization

recommendations but assume that the patient's oncologist is administering the vaccine series, the community clinicians may be less likely to address the HPV vaccination issue with the patient and her family. The question then arises, if adolescent cancer survivors were offered the HPV vaccination by their oncologist or other medical providers at annual ACT visits, would the vaccination rate for survivors then increase or exceed that of the general population?

Additionally concerning was the finding that the community control sample of mothers also endorsed vaccination rates lower than the national average. Although it is unclear why this finding emerged, one possible explanation is the present study's small sample size of control mothers ($n = 44$) is unlikely to be as accurate of a representation of the general population of adolescent females as the CDC's sample of over 9,600 females with vaccination records.

Intent is an indication of a person's readiness to engage in a particular behavior (Ajzen, 1991), and a recent study demonstrated high parental intentions to vaccinate daughters against HPV (Gerend, Weibley, & Bland, 2009). In a sample of first-year college females, Juraskova and colleagues (2011) reported that when asked whether they intended to receive the HPV vaccination in the near future, mean intent scores were significantly higher following receipt of an HPV information leaflet. The present study assessed mothers' intent to vaccinate daughters against HPV in the future, and found no significant difference in future intent to vaccinate for HPV between groups, indicating that mothers whose daughters have survived cancer intended to vaccinate their child against HPV at similar rates as mothers of healthy daughters. Consideration should be made of the fact that mothers of healthy control daughters were recruited as an

acquaintance sample, and were therefore familiar with the participants in the comparison group. It is possible that mothers in both groups have similar attitudes toward HPV vaccination and even those whose daughters receive medical care from providers in their home community, where HPV vaccinations may be readily available, have decided not to vaccinate their daughters as of yet. It is important to note that the mean response for intentions was between 'Not Sure' and 'Likely,' indicating that, on average, most mothers are somewhat undecided or are leaning towards potentially vaccinating daughters in the future.

The advancements in the treatment of childhood cancer have resulted in survivors living well into adulthood. Given that the median age of cervical cancer diagnosis is between 47 to 48 years-of-age and that childhood cancer survivors are at increased risk for persistent HPV infection, there is a need to better understand factors which influence vaccination intent and to assess for factors that may improve HPV vaccination rates among survivors. The present study compared all participating mothers in cancer and control groups for differences on medical and demographic factors, cervical cancer/HPV knowledge, health beliefs, and self-efficacy because these variables had yet to be examined, but may have important implications, among survivors of childhood cancer.

In general, few differences between cancer and control groups emerged, indicating that the acquaintance control sample successfully recruited mothers of similar demographic backgrounds to the mothers of cancer survivors. Results also indicated that the two groups were not significantly different with respect to maternal medical care. Although no significant difference was found between groups on HPV-related knowledge scores, participating mothers were relatively unknowledgeable regarding HPV and HPV-

related health risks, as mean knowledge levels were fairly low. Previous published reports have also demonstrated low levels of HPV knowledge among women (Allen et al., 2009). No differences were found between groups with regard to Health Belief factors including perceived barriers to HPV vaccination, perceived benefits to HPV vaccination for their daughters, or mothers' self-efficacy to vaccinate daughters.

There were some notable differences between groups of mothers. Specifically, the number of white and minority participants in the cancer and control groups differed significantly. Although the survivorship group included significantly more ethnic minority mothers than the healthy control group, the distribution of children diagnosed with cancer was consistent with the US population. Results also indicated that groups differed based on perceived susceptibility as well as severity. Mothers of cancer survivors rated their daughters as more vulnerable to HPV-related health risks than mothers of healthy control daughters, yet indicated less severity for HPV and related health risks for their daughters than mothers of healthy daughters. In other words, mothers whose daughters survived childhood cancer believed that their daughters were more likely to contract an HPV infection than healthy daughters; however, they also believed HPV infection to be less severe or pose fewer health consequences to their daughter than mothers of healthy daughters. This finding may be explained by the fact that survivors of childhood cancers are indeed at an increased risk for HPV infection due to immunosuppression, and mothers of survivors are perhaps aware that their daughter's compromised immune system places them at higher risk for infections.

Mothers of childhood cancer survivors may also worry that their daughters will develop a second malignancy. Recently published findings from the Childhood Cancer

Survivor Study (CCSS) indicate that survivors of childhood cancer maintain a nearly 1 in 10 chance of developing a subsequent neoplasm, and those surviving the first subsequent neoplasm remain at risk for development of multiple subsequent neoplasms (Armstrong et al., 2011). It is possible that survivors' mothers received messages from oncologists stating that their daughter is more susceptible to contracting illnesses than healthy peers and HPV infections specifically. Families may gain firsthand experience living with immunocompromise during treatment for cancer, as it is not uncommon that patients are required to wear protective masks in order to attend school or interact with peers. This may also contribute to increased perceptions of susceptibility to infectious disease.

Other factors specific to HPV and STI's may also contribute to the finding that mothers of survivors rated their daughters as more susceptible to HPV than mothers of healthy controls. For example, mothers of cancer survivors may be more aware of the fact that HPV is the most common sexually transmitted infection or may have a family history of HPV and/or cervical cancer. It is also possible that mothers of survivors maintain perceptions of their daughter's sexual behavior which place their daughter at increased risk for contracting HPV or perhaps their daughter has already been diagnosed with an HPV infection.

Less perceived severity for HPV and HPV-related health risks for childhood cancer survivors may be explained as mothers viewing cancer diagnosis and treatment as the greatest health risk for their daughters and that HPV infection is less severe in comparison. In other words, mothers of survivors may have lower HPV-related severity scores due to an overall sense of perceived invulnerability or resiliency – even if their daughter contracts an HPV infection, she has successfully conquered cancer once before,

so HPV is a much less frightening diagnosis and less daunting to treat. A sense of resiliency in adolescent cancer survivors has been related to quality of decision-making for risk behaviors (Hollen, Hobbie, Finley, & Hiebert, 2001). Mothers who believe that their daughter will not engage in risky sexual behavior may also endorse less perceived severity related to HPV infection. These mothers may already hold the belief that their daughter's cancer diagnosis poses serious medical and social repercussions, therefore any consequences related to HPV infection may seem more tolerable. If mothers of childhood cancer survivors are unacquainted with anyone with a personal history of HPV infection or cervical cancer, it is possible that these mothers are also unaware of the consequences related to HPV infections. It is also possible that mothers of survivors are indeed unaware of the link between HPV and cervical cancer, or perhaps are aware that many women are able to clear an HPV infection without serious consequences.

Additionally, survivors of childhood cancer are now living longer and the median age of CCSS participants is 32 years-of-age, meaning that many have yet to reach an age when cancer rates begin to rise in the general population (Armstrong et al., 2011), particularly given that the median age for cervical cancer expression is 48 years. Consequently, survivor specialists may not be educating their patients on their risk for cervical cancer, as this has yet to be demonstrated among survivors despite the research demonstrating their increased risk for HPV-related complications. Unfortunately, given that childhood cancer survivors are at increased risk for HPV infection and related complications, their inability to clear an HPV infection may actually pose HPV health concerns of greater severity. As cervical cancer is one of a select group of cancers for which risk reduction could occur by behavioral means (e.g., reducing risky sexual

behavior and completing in HPV vaccination), survivors may be able to alter their risk for future HPV-related complication.

Further analyses revealed that, of vaccine naïve daughters, future intent to vaccinate was correlated with daughter's age, perceived severity, perceived barriers, perceived benefits, and self-efficacy. All correlations were in the expected directions; intent was negatively correlated with daughter's age and perceived barriers, and positively correlated with perceived severity, benefits, and self-efficacy. Mothers with younger daughters and those who endorsed greater perceived severity of HPV infection, fewer perceived barriers to vaccination, greater perceived benefits to vaccination, and higher levels of self-efficacy had greater intent to vaccinate their daughters against HPV in the future.

Previous literature has indicated that daughter's age is related to HPV vaccination intent; however, unlike in the present study, Reiter and colleagues (2010) demonstrated older age of daughter to be related to intent to vaccinate in the future. Furthermore, researchers have also found no differences in intent to vaccinate by daughter's age group (Gottlieb et al., 2009). Several hypotheses have been developed in interpreting this finding herewithin specific to the inverse relationship between age and vaccination intent. Of note, the cited studies measured daughter's age as a categorical variable (i.e., 10 to 12 years, 13 to 15 years, and 16 to 17 or 18 years of age), whereas the present study measures daughter's age as a continuous variable (9 to 17 years of age). All daughters of participating mothers were of eligible age to receive the vaccine. Mothers with younger daughters may have endorsed higher intent to vaccinate in the future because there will be time for additional studies to evaluate the safety and efficacy of the relatively new

immunization before their daughter ages out of the recommended window for vaccination. As the HPV vaccine becomes more widely marketed, it is likely that mothers with younger daughters have been exposed to more cues to action for the vaccine series during the timeframe when their daughter is within the recommended age range for vaccination; perhaps older daughters did not receive key vaccination messages from their physicians during their preadolescent years when the vaccine was first available, and have now "aged out" of the 12-13 year age range which is ideal for vaccination.

Additionally, it is possible that the relation between intent to vaccinate and daughter's age is mediated by perceptions of daughter's sexual activity. Mothers may be confident that younger daughters are not yet sexually active and would therefore benefit from vaccination; whereas mothers with older daughters may deem vaccination unnecessary if their daughters are currently sexually active and likely to already have been exposed to HPV. This should be further examined in future studies. Mothers with older daughters may require additional educational information regarding the importance of vaccinating females prior to the onset of sexual activity in order to achieve greatest protection. Mothers may also benefit from reminders that even if their daughters are sexually active, it is unlikely that they have been exposed to all 4 strains of HPV against which Gardasil protects.

The inverse relation between daughter's age and intent to vaccinate may also be explained by a developmental shift in responsibility for medical care. Younger daughters may still receive regular medical care from pediatricians who have likely discussed the HPV vaccine with the patient's family. As age increases, so does an adolescent's input into her medical care (Humiston & Rosenthal, 2005). With regard to the familial

decision-making process for children's healthcare, mothers maintain a certain sense of influence over younger daughters' medical care; whereas more negotiating may be required to convince an older adolescent to provide vaccination assent to initiate and complete the vaccine series. Furthermore, as children grow older, they are less likely to attend medical appointments (Ziv, Boulet, & Slap, 1999) and it is possible that older adolescents are beginning to be seen individually by their primary care physician for behavioral risk counseling, such that their parent does not have the opportunity to hear immunization messages from the physician.

The present study's findings are similar to previous research correlating Health Belief factors to intent (Gerend et al., 2007; Juraskova et al., 2011; Kahn et al., 2008), and nearly all health belief factors were included into the regression model. Mothers in the present study were more likely to intend to vaccinate daughters against HPV if they held higher beliefs in the severity of HPV infections. This implies that information regarding the serious health risks that persistent HPV infection poses for their daughter could be emphasized further in order to encourage mothers to vaccinate their daughters, a notion especially important to consider for the high risk cancer sample. Furthermore, when mothers perceived fewer obstacles to obtaining HPV immunizations, they were more likely to intend to vaccinate daughters in the future.

Mothers were more likely to endorse higher levels of intent to vaccinate in the future if their perception was that HPV immunization offers protective health benefits for their daughter. Mothers with higher perceived benefits to HPV immunization may also hold a belief in the health protection offered by immunizations in general. When examining individual benefits of the vaccine, mothers rated a reduction in the chance of

their daughter getting cervical cancer as the greatest benefit, so it may be that mothers with greater intent to vaccinate daughters also desire to engage behaviors which support a public health effort to reduce cancers in women. Perceived benefits have previously been reported as the strongest predictor of HPV vaccine acceptability (de Visser & McDonnell, 2008; Dempsey et al., 2006), and findings from the present study substantiate such reports as regression analyses revealed perceived benefits to have the greatest beta weight among predictors of future HPV vaccination intent.

Similarly, when mothers endorse greater self-efficacy and believe they have the means and are able to successfully vaccinate their child, they are more likely to intend to immunize their daughter against HPV in the future. These findings continue to support the notion that public health efforts and health care providers should focus on addressing the concerns that mothers have regarding the safety and efficacy of the HPV immunization while emphasizing the potential health benefits to protecting their daughters from the serious types of HPV (Dempsey, Abraham, Dalton, & Ruffin, 2009; Tissot et al., 2007).

Previous studies have demonstrated that strong physician recommendation of the HPV immunization is related to maternal acceptance of the vaccine (Dempsey et al., 2009) and that physician recommendation is correlated with vaccine uptake (Gerend et al., 2009; Reiter, Brewer, Gottlieb, McRee, & Smith, 2009). In the present study, however, physician recommendation was not found to correlate with future intent to vaccinate. Perhaps more importantly, fewer than half of all mothers endorsed that their daughter's physician had recommended HPV vaccination, despite indicating that their daughters have received all recommended childhood vaccines. It may be that without a

medical provider's suggestion to immunize their daughter, mothers are unaware of the recommendation that all females receive the vaccine series. In order to enhance vaccination among childhood cancer survivors, medical providers will need to address the importance of HPV immunization in this population. Although the current study did not examine this specifically, it is possible that some mothers received a recommendation from their daughter's physician and yet did not vaccinate. Future efforts are needed to examine differences in those mothers who did/did not receive a vaccine recommendation and those who did/did not have daughter vaccinated. Such efforts may identify the best strategy for physicians to utilize when recommending HPV vaccination to mothers in order to increase the likelihood that they will adhere to the recommendation.

When controlling for daughter's age and daughter's history of cancer (i.e., childhood cancer survivor or healthy control), a hierarchical linear regression analysis revealed that younger age and perceptions of increased vaccine benefit uniquely predicted intent to vaccinate daughters. When predictors were examined separately for mothers of cancer survivors and mothers of healthy daughters, no group differences emerged, indicating that factors which influence mothers' intent to vaccinate healthy daughters appear to be the same for mothers of adolescent survivors of childhood cancer. Given that age and perceived benefits were unique predictors of intent, future interventions aimed at increasing HPV vaccination among the general population as well as among cancer survivors should seek to highlight the benefits of HPV vaccination, particularly for older, sexually naïve females. For survivors of childhood cancer, this may potentially be done during medical visits with her oncologist. It is important for health care providers to assess mothers' perceived benefits to HPV vaccination, and seek to

provide mothers with factual information regarding HPV immunization recommendations. Physicians are often unable to spend a great length of time with any one patient and/or family and may turn to clinical psychologists and other health care providers, trained in motivational interviewing, to assist mothers in creating discrepancy and resolving any ambivalence regarding vaccinating daughters against HPV.

When interpreting these findings, one should consider the study's limitations. As in other cross-sectional study designs, only associations, not causalities, can be determined between medical, demographic, and health belief factors and intent. Due to the small sample of this study, results should be interpreted with caution, and future studies should seek to enroll higher numbers of participants, as there may be advantages to having a larger control sample of healthy daughters. Larger sample sizes will provide future studies with greater power to detect differences among groups of healthy females and those with a history of childhood cancer, and findings will have greater generalizability. By recruiting a control group of acquaintance mothers, regional differences in vaccination rates could not be accounted for. Vaccination coverage for 13-17 year old adolescents has been shown to vary by state (Centers for Disease Control and Prevention, 2010b). Institutional review board approval for the present study placed great emphasis on participant confidentiality and therefore data were not collected with regard to the control participants' state of residence; however, given that all demographic variables save for ethnicity were found to be consistent between groups, this is perhaps less of a concern for the present study. Future studies may wish to consider examining regional differences in vaccination rates.

Additionally, all cancer participants were recruited from a single site. Findings may not generalize to other pediatric cancer survivors or healthy daughters not acquainted with a childhood cancer survivor. It is important to note that an emphasis is placed on research at the recruitment institution used for the present study, and families of childhood cancer survivors are accustom to completing study questionnaires as part of their annual visit. There may be potential differences in HPV vaccination completion and intent between mothers of cancer survivors who did and did not complete this study, among mothers whose daughters receive oncology care at different institutions, and even among survivors of differing cancer diagnoses. This study highlights the importance of recruiting control samples of healthy females from the general population in order to further examine differences in intent to vaccinate between survivors and the general population.

Methodological issues, such as the way intent was measured, may not have allowed significant associations to emerge. The purpose behind measuring intent with four items was to also gather data related to mothers' readiness to engage in vaccination; however, there appeared to be some confusion in questionnaire instructions, as many mothers did not complete all four intention items. Because a total intent sum score could not be calculated for all participating mothers with vaccine naïve daughters, the decision was made to use only the final intent item to measure 'future' intent. Mothers who reported higher intentions to vaccinate daughters within the next month to year were excluded in this process, thereby possibly deflating actual vaccine intentions. For example, a mother may have endorsed that she is 'Very Likely' to have her daughter vaccinated within the next month and 'Definitely Will' vaccinate her daughter within the

next 6 months, but then failed to complete the final two intent items. As a result, her data were not included in the final analyses, although she endorsed high intent to vaccinate her daughter.

Several improvements should be made for future studies examining HPV vaccination among survivors of childhood cancer. A longitudinal study design reassessing vaccination rates among survivors and important factors related to vaccine intent over time would be beneficial given that HPV vaccination rates and attitudes have not been assessed among families of childhood cancer survivors until now. Such a design would also monitor for changes in attitudes toward vaccination and vaccine uptake within this population. Future studies should also strive for larger sample sizes with more equivalent numbers of participants in survivorship and control samples.

Comparisons between survivors and healthy adolescent females may continue to be monitored for any differences that may arise. Future studies should continue to examine the predictive nature of the factors included in the conceptual model examined in the present study on intent as well as vaccine initiation and completion. Such studies should also examine the predictive nature of additional factors not included in the present study (i.e., cues to action, socioenvironmental factors, sexual communication, time since diagnosis, as well as treatment intensity) on intent to vaccinate for HPV, as well as engagement in immunization. Additionally, relations between vaccine intentions and engagement in vaccine initiation and completion will need to be examined among childhood cancer survivors.

Mothers' perceptions of daughters' sexual behavior may be a key factor to assess in future studies, as well; as such perceptions may influence mothers' intent to vaccinate

daughters against STI's. Similarly, communication between mothers and daughters in general, with regard to sexual topics, and with regard to HPV and cervical cancer specifically should be assessed for its role in vaccinating adolescent females against HPV.

Future studies may also evaluate the utility of providing mothers with an HPV information sheet. Providing mothers with factual knowledge regarding HPV health risks and immunization may influence intentions for vaccinating daughters against HPV in the future. Mothers can share the fact sheet with partners and significant others, which in turn may increase the likelihood of discussion of vaccination within partnerships and families. Adjusting for time since vaccine licensure, it is necessary to test the efficacy of a knowledge intervention. Future interventions aimed at increasing HPV vaccination rates among childhood cancer survivors may seek to provide the HPV vaccine series at pediatric oncology centers for patients who are able to return to clinic for the 3 shot series. Medical providers at such institutions may also coordinate care with medical providers at local health care facilities for patient families who are unable to return for the series of injections.

To further our knowledge base, vaccination intent should be measured in ways such that more participant data are eligible for inclusion in the analyses. Future studies should strive to clarify that all items are to be answered, simplify the measurement of intent by simply assessing future intent with one item, or perhaps utilize the collected data in a more meaningful way by examining associations of varying levels of intent. The use of more psychometrically sound and validated instruments of intentions will also be beneficial.

As mentioned previously, the literature is beginning to address the increased risk of HPV related complications among childhood cancer survivors, necessitating additional research to demonstrate increased rates of cervical cancer in survivors of childhood cancer as the cohort of survivors reaches ages when cancer rates begin to rise in the general population. At present, there is a paucity of research establishing the immunogenicity of the HPV vaccination among immunocompromised populations. In HIV-infected children, differences have been noted in quadrivalent HPV vaccine seroconversion, as titers against HPV subtypes 6 and 18 were demonstrated to be 30-50% lower than age matched controls (Garland et al., 2007; Levin et al., 2010) A Phase II study is warranted to examine the safety, immunogenicity, and tolerability as well as scheduling and dosage of the HPV vaccine among childhood cancer survivors.

In conclusion, findings of the current study further our understanding of familial decision-making about child and adolescent health through identification of factors influencing HPV vaccination among female survivors of childhood cancer and healthy controls. Future interventions designed to increase HPV vaccination among childhood cancer survivors may draw upon the study findings to enhance immunization rates and mother's intent to vaccinate daughters in the future.

References

Aiken, L. S., & West, S. G. (1991). *Multiple regression: Testing and interpreting interactions*. Newbury Park, London: Sage.

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes, 50*, 179-211.

Allen, J. D., Mohllajee, A. P., Shelton, R. C., Othus, M. K. D., Fontenot, H. B., & Hanna, R. (2009). Stage of adoption of the human papillomavirus vaccine among college women. *Preventive Medicine, 48*, 420-425.

American College of Obstetricians and Gynecologists. (2004). Patient Education Pamphlet. Retrieved July 7, 2008, from http://www.acog.org/publications/patient_education/bp161.cfm

Armstrong, G. T., Liu, W., Leisenring, W., Yasui, Y., Hammond, S., Bhatia, S., et al. (2011). Occurrence of Multiple Subsequent Neoplasms in Long-Term Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/21709189

Ault, K. A. (2007). Long-term efficacy of human papillomavirus vaccination. *Gynecologic Oncology, 107*, 27-30.

Barkley, R. A., Fischer, M., Smallish, L., & Fletcher, K. (2006). Young adult outcome of hyperactive children: Adaptive functioning in major life activities. [Research report]. *J. Am. Acad. Child Adolesc. Psychiatry, 45*(2), 192-202.

Bhatia, S., Louie, A. D., Bhatia, R., O'Donnell, M. R., Fung, H., Kashyap, A., et al. (2001). Solid cancers after bone marrow transplantation. *Journal of Clinical Oncology, 19*, 464-471.

Boonstra, H., & Nash, E. (2000). Minors and the right to consent to health care. *The Guttmacher Report on Public Policy, 3*, 1-6.

Brabin, L., Roberts, S. A., Farzaneh, F., & Kitchener, H. C. (2006). Future acceptance of adolescent human papillomavirus vaccination: A survey of parental attitudes. *Vaccine, 24*, 3087-3094.

Castellino, S. M., Casillas, J., Hudson, M. M., Mertens, A. C., Whitton, J., Brooks, S. L., et al. (2005). Minority adult survivors of childhood cancer: a comparison of long-term outcomes, health care utilization, and health-related behaviors from the childhood cancer survivor study. *Journal of Clinical Oncology, 23*, 6499-6507.

CDC. (2007). Quadrivalent human papillomavirus vaccine: Recommendations of the Advisory Committee on Immunization Practices (ACIP). *Morbidity and Mortality Weekly Report, 56*(No. RR-2), 1-26.

Centers for Disease Control and Prevention. (2010a). FDA licensure of bivalent Human Papillomavirus Vaccine (HPV2, Cervarix) for use in females and updated HPV vaccination recommendations from the Advisory Committee on Immunization Practices (ACIP). *Morbidity and Mortality Weekly Report, 79*, 626-629.

Centers for Disease Control and Prevention. (2010b). National, state, and local area vaccination coverage among adolescents aged 13-17 years --- United States, 2009. *MMWR Morb Mortal Wkly Rep, 59*, 1018-1023.

Children's Oncology Group. (2006). Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. Retrieved September 20, 2008, from http://www.survivorshipguidelines.org/

Constantine, N. A., & Jerman, P. (2007). Acceptance of human papillomavirus vaccination among Californian parents of daughters: A representative statewide analysis. *Journal of Adolescent Health, 40*, 108-115.

Cox, Cox, A. D., Sturm, L., & Zimet, G. (2010). Behavioral interventions to increase HPV vaccination acceptability among mothers of young girls. *Health Psychology, 29*, 29-39.

Davis, K., Dickman, E. D., Ferris, D., & Dias, J. K. (2004). Human papillomavirus vaccine acceptability among parents of 10- to 15-year-old adolescents. *Journal of lower genital tract disease, 8*, 188-194.

de Visser, R., & McDonnell, E. (2008). Correlates of parents' reports of acceptability of human papilloma virus vaccination for their school-aged children. *Sexual Health, 5*, 331-338.

Dempsey, A. F., Abraham, L. M., Dalton, V., & Ruffin, M. (2009). Understanding the Reasons Why Mothers Do or Do Not Have Their Adolescent Daughters Vaccinated Against Human Papillomavirus. *Annals of Epidemiology, 19*(8), 531-538.

Dempsey, A. F., Zimet, G. D., Davis, R. L., & Koutsky, L. (2006). Factors that are associated with parental acceptance of human papillomavirus vaccines: a randomized intervention study of written information about HPV. *Pediatrics, 117*, 1486-1493.

Dunne, E. F., Unger, E. R., Sternberg, M., McQuillan, G., Swan, D. C., Patel, S. S., et al. (2007). Prevalence of HPV infection among females in the United States. *Journal of the American Medical Association, 297*, 813-819.

FDA. (2006a). FDA Licenses New Vaccine for Prevention of Cervical Cancer and Other Diseases in Females Caused by Human Papillomavirus: Rapid Approval Marks Major Advancement in Public Health. Retrieved June 8, 2008, from http://www.fda.gov/bbs/topics/NEWS/2006/NEW01385.html

FDA. (2006b). HPV (human papillomavirus). Retrieved June 18, 2008, from http://www.fda.gov/womens/getthefacts/hpv.html

FDA. (2010). FDA licensure of quadrivalent human papillomavirus vaccine (HPV4, Gardasil) for use in males and guidance from the Advisory Committee on Immunization Practices (ACIP). *Morbidity and Mortality Weekly Report, 59*, 630-632.

Flory, K., Molina, B. S. G., Pelham, W. E., Jr., Gnagy, E., & Smith, B. (2006). Childhood ADHD predicts risky sexual behavior in young adulthood. *Journal of Clinical Child and Adolescent Psychology, 35*, 571-577.

Fujimura, M., Ostrow, R. S., & Okagaki, T. (1991). Implication of human papillomavirus in postirradiation dysplasia. *Cancer, 68*, 2181-2185.

Gamble, H. L., Klosky, J. L., Parra, G. R., & Randolph, M. E. (2009). Factors influencing familial decision-making regarding Human Papillomavirus vaccination. *Journal of Pediatric Psychology, 35*, 704-715.

Garland, S. M., Hernandez-Avila, M., Wheeler, C. M., Perez, G., Harper, D. M., Leodolter, S., et al. (2007). Quadrivalent vaccine against human papillomavirus to prevent anogenital diseases. *New England Journal of Medicine, 356*, 1928-1943.

Gerend, M. A., Lee, S. C., & Shepherd, J. E. (2007). Predictors of human papillomavirus vaccination acceptability among underserved women. *Sexually Transmitted Diseases, 34*, 468-471.

Gerend, M. A., Weibley, E., & Bland, H. (2009). Parental response to Human Papillomavirus vaccine availability: Uptake and intentions. *Journal of Adolescent Health, 45*, 528-531.

Glanz, K., Rimer, B. K., & Lewis, F. M. (Eds.). (2002). *Health Behavior and Health Education: Theory, Research, and Practice* (3rd ed.). San Francisco: Jossey-Bass.

Gottlieb, S. L., Brewer, N. T., Sternberg, M. R., Smith, J. S., Ziarnowski, K., Liddon, N., et al. (2009). Human Papillomavirus vaccine initiation in an area with elevated rates of cervical cancer. *Journal of Adolescent Health, 45*, 430-437.

Harper, D. M., Franco, E. L., Wheeler, C. M., Moscicki, A. B., Romanowski, B., Roteli-Martins, C. M., et al. (2006). Sustained efficacy up to 4.5 years of a bivalent L1 virus-like particle vaccine against human papillomavirus types 16 and 18: Follow-up from a randomised control trial. *Lancet, 367*, 1247-1255.

Hollen, P. J., Hobbie, W. L., Finley, S. M., & Hiebert, S. M. (2001). The relationship of resiliency to decision making and risk behaviors of cancer-surviving adolescents. *Journal of Pediatric Oncology Nursing, 18*, 188-204.

Huang, C. M. (2008). Human papillomavirus and vaccination. *Mayo Clinic Proceedings, 83*, 701-706.

Hudson, M. M., Mertens, A. C., Yasui, Y., Hobbie, W., Chen, H., Gurney, J. G., et al. (2003). Health status of adult long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Journal of the American Medical Association, 290*, 1583-1592.

Humiston, S. G., & Rosenthal, S. L. (2005). Challenges to vaccinating adolescents: vaccine implementation issues. *The Pediatric Infectious Disease Journal, 24*, S134-S140.

Juraskova, I., Bari, R. A., O'Brien, M. T., & McCaffery, K. J. (2011). HPV vaccine promotion: Does referring to both cervical cancer and genital warts affect intended and actual vaccination behavior? *Women's Health Issues, 21*, 71-79.

Kahn, J. A., Rosenthal, S. L., Jin, Y., Huang, B., Namakydoust, A., & Zimet, G. D. (2008). Rates of human papillomavirus vaccination, attitudes about vaccination, and human papillomavirus prevalence in young women. *Obstetrics & Gynecology, 111*, 1103-1110.

Kahn, J. A., Rosenthal, S. L., Succop, P. A., Ho, G. Y. F., & Burk, R. D. (2002). Mediators of the association between age of first sexual intercourse and subsequent Human Papillomavirus infection. *Pediatrics, 109*, e5.

Katz, R. L., Veanattukalathil, S., & Weiss, K. M. (1987). Human papillomavirus infection and neoplasia of the cervix and anogenital region in women with Hodgkin's disease. *Acta Cytologica, 31*, 845-854.

Klosky, J. L., Gamble, H. L., Spunt, S. L., Randolph, M. E., Green, D. M., & Hudson, M. M. (2009). Human papillomavirus vaccination in survivors of childhood cancer. *Cancer, 115*, 5627-5636.

Koutsky, L. A., & Harper, D. M. (2006). Chapter 13: Current findings from prophylactic HPV vaccine trials. *Vaccine, 24*, 114-121.

Lazcano-Ponce, E., Rivera, L., Arillo-Santillan, E., Salmeron, J., Hernandez-Avila, M., & Munoz, N. (2001). Acceptability of a human papillomavirus (HPV) trial vaccine among mothers of adolescents in Cuernavaca, Mexico. *Archives of Medical Research, 32*, 243-247.

Levin, M. J., Moscicki, A. B., Song, L. Y., Fenton, T., Meyer, W. A., 3rd, Read, J. S., et al. (2010). Safety and immunogenicity of a quadrivalent human papillomavirus (types 6, 11, 16, and 18) vaccine in HIV-infected children 7 to 12 years old. *Journal of Acquired Immune Deficiency Syndromes, 55*, 197-204.

Mariam, A. (2005). Cervical cancer vaccines available in 2007. *Drug Discovery Today, 10*, 949-950.

Markowitz, L. E., Dunne, E. F., Saraiya, M., Lawson, H. W., Chesson, H., & Unger, E. R. (2007). Quadrivalent human papillomavirus vaccine: Recommendations of the Advisory Committee on Immunization Practices (ACIP). *Morbidity and Mortality Weekly Report Recommendations and Reports, 56*, 1-24.

Munoz, N., Bosch, F. X., de Sanjose, S., Herrero, R., Castellsague, X., Shah, K. V., et al. (2003). Epidemiologic classification of human papillomavirus types associated with cervical cancer. *New England Journal of Medicine, 348*, 518-527.

National Cancer Institute. (2007). National Cancer Institute fact sheet 5.16. Retrieved July 7, 2008, from http://www.cancer.gov/cancertopics/factsheet/detection/Pap-test

Oeffinger, K. C., Mertens, A. C., Hudson, M. M., Gurney, J. G., Casillas, J., Chen, H., et al. (2004). Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Annals of Family Medicine, 2*, 61-70.

Palefsky, J. (2007). Human papillomavirus infection in HIV-infected persons. *Topics in HIV Medicine, 15*, 130-133.

Palefsky, J. (2009). Human papillomavirus-related disease in people with HIV. *Current Opinion in HIV and AIDS, 4*, 52-56.

Quayle, A. J. (2002). The innate and early immune response to pathogen challenge in the female genital tract and the pivotal role of epithelial cells. *Journal of Reproductive Immunology, 57*, 61-79.

Reisinger, K. S., Block, S. L., Lazcano-Ponce, E., Samakoses, R., Esser, M. T., Erick, J., et al. (2007). Safety and persistent immunogenicity of a quadrivalent human papillomavirus types 6, 11, 16, 18 L1 virus-like particle vaccine in preadolescents and adolescents: a randomized controlled trial. *The Pediatric Infectious Disease Journal, 26*, 201-209.

Reiter, P. L., Brewer, N. T., Gottlieb, S. L., McRee, A. L., & Smith, J. S. (2009). Parents' health beliefs and HPV vaccination of their adolescent daughters. *Social Science and Medicine, 69*, 475-480.

Reiter, P. L., Cates, J. R., McRee, A.-L., Gottlieb, S. L., Shafer, A., Smith, J. S., et al. (2010). Statewide HPV vaccine initiation among adolescent females in North Carolina. *Sexually Transmitted Diseases, 37*, 549-556.

Ries, L. A. G., Melbert, D., Krapcho, M., Stinchcomb, D. G., Howlader, N., Horner, M. J., et al. (Eds.). (2006). *SEER Cancer Statistics Review, 1975-2003, National Cancer Institute*. Bethesda, MD.

Rimer, B. K., & Glanz, K. (2005). Theory at a glance: A guide for health promotion practice (Second edition) Available from http://www.cancer.gov/PDF/481f5d53-63df-41bc-bfaf-5aa48ee1da4d/TAAG3.pdf

Roka, S., Rasoul-Rockenschaub, S., Roka, J., Kirnbauer, R., Mühlbacher, F., & Salat, A. (2004). Prevalence of anal HPV infection in solid-organ transplant patients prior to immunosuppression. *Transplant International, 17*, 366-369.

Rosenthal, S. L., Rupp, R., Zimet, G. D., Meza, H. M., Loza, M. L., Short, M. B., et al. (2008). Uptake of HPV vaccine: Demographics, sexual history and values, parenting style, and vaccine attitudes. *Journal of Adolescent Health, 43*, 239-245.

Sasadeusz, J., Kelly, H., Szer, J., Schwarer, A. P., Mitchell, H., & Grigg, A. (2001). Abnormal cervical cytology in bone marrow transplant recipients. *Bone Marrow Transplant, 28*, 393-397.

Saslow, D., Castle, P. E., Cox, J. T., Davey, D. D., Einstein, M. H., Ferris, D. G., et al. (2007). American Cancer Society guideline for human papillomavirus (HPV) vaccine use to prevent cervical cancer and its precursors. *CA: A Cancer Journal for Clinicians, 57*, 7-28.

Sauvageau, C., Duval, B., Gilca, V., Lavoie, F., & Ouakki, M. (2007). Human papilloma virus vaccine and cervical cancer screening acceptability among adults in Quebec, Canada. *BMC Public Health, 7*, 304.

Savani, B. N., Stratton, P., Shenoy, A., Kozanas, E., Goodman, S., & Barrett, A. J. (2008). Increased risk of cervical dysplasia in long-term survivors of allogeneic stem cell transplantation—Implications for screening and HPV vaccination. *Biology of Blood and Marrow Transplantation : Journal of the American Society for Blood and Marrow Transplantation, 14*, 1072-1075.

Seshadri, L., George, S. S., Vasudevan, B., & Krishna, S. (2001). Cervical intraepithelial neoplasia and human papilloma virus infection in renal transplant recipients. *Indian Journal of Cancer, 38*, 92-95.

Sheinfeld Gorin, S., Franco, R., & Westhoff, C. (2008, May 30-June 3, 2008). *HPV Vaccinations one year post FDA approval.* Paper presented at the 2008 American Society of Clinical Oncology Annual Meeting, Chicago, IL.

Slomovitz, B. M., Sun, C. C., Frumovitz, M., Soliman, P. T., Schmeler, K. M., Pearson, H. C., et al. (2006). Are women ready for the HPV vaccine? *Gynecologic Oncology, 103*, 151-154.

Socie, G., Curtis, R. E., Deeg, H. J., Sobocinski, K. A., Filipovich, A. H., Travis, L. B., et al. (2000). New malignant diseases after allogeneic marrow transplantation for childhood acute leukemia. *Journal of Clinical Oncology, 18*, 348-357.

Tissot, A. M., Zimet, G. D., Rosenthal, S. L., Bernstein, D. I., Wetzel, C., & Kahn, J. A. (2007). Effective strategies for HPV vaccine delivery: The views of pediatricians. *Journal of Adolescent Health, 41*, 119-125.

Villa, L. L. (2007). Overview of the clinical development and results of a quadrivalent HPV (types 6, 11, 16, 18) vaccine. *International Journal of Infectious Diseases, 11*, 17-S25.

Villa, L. L., Costa, R. L., Petta, C. A., Andrade, R. P., Ault, K. A., Giuliano, A. R., et al. (2005). Prophylactic quadrivalent human papillomavirus (types 6, 11, 16, and 18) L1 virus-like particle vaccine in young women: A randomised double-blind placebo-controlled multicentre phase II efficacy trial. *Lancet Oncology, 6*, 271-278.

Villa, L. L., Costa, R. L., Petta, C. A., Andrade, R. P., Paavonen, J., Iversen, O. E., et al. (2006). High sustained efficacy of a prophylactic quadrivalent human papillomavirus types 6/11/16/18 L1 virus-like particle vaccine through 5 years of follow-up. *British Journal of Cancer, 95*, 1459-1466.

Watson, M., Saraiya, M., Ahmed, F., Cardinez, C. J., Reichman, M. E., Weir, H. K., et al. (2008). Using population-based cancer registry data to assess the burden of human papillomavirus-associated cancers in the United States: Overview of methods. *Cancer, 113*, 2841-2854.

Weinstock, H., Berman, S., & Cates, W., Jr. (2004). Sexually transmitted diseases among American youth: Incidence and prevalence estimates, 2000. *Perspectives on Sexual and Reproductive Health, 36*, 6-10.

Winer, R. L., Lee, S.-K., Hughes, J. P., Adam, D. E., Kiviat, N. B., & Koutsky, L. A. (2003). Genital Human Papillomavirus Infection: Incidence and Risk Factors in a Cohort of Female University Students. *American Journal of Epidemiology, 157*, 218-226.

Wulf, D. (2002). *In their own right: Addressing the sexual and reproductive health needs of American men*. New York: Alan Guttmacher Institute.

Yeazel, M. W., Oeffinger, K. C., Gurney, J. G., Mertens, A. C., Hudson, M. M., Emmons, K. M., et al. (2004). The cancer screening practices of adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Cancer, 100*, 631-640.

Zebrack, B. J., Casillas, J., Nohr, L., Adams, H., & Zeltzer, L. K. (2004). Fertility issues for young adult survivors of childhood cancer. *Psychooncology, 13*, 689-699.

Zimet, G. D., Shew, M. L., & Kahn, J. A. (2008). Appropriate use of cervical cancer vaccine. *Annual Review of Medicine, 59*, 223-236.

Ziv, A., Boulet, J. R., & Slap, G. B. (1999). Utilization of physician offices by adolescents in the United States. *Pediatrics, 104*, 35-42.

Appendix A

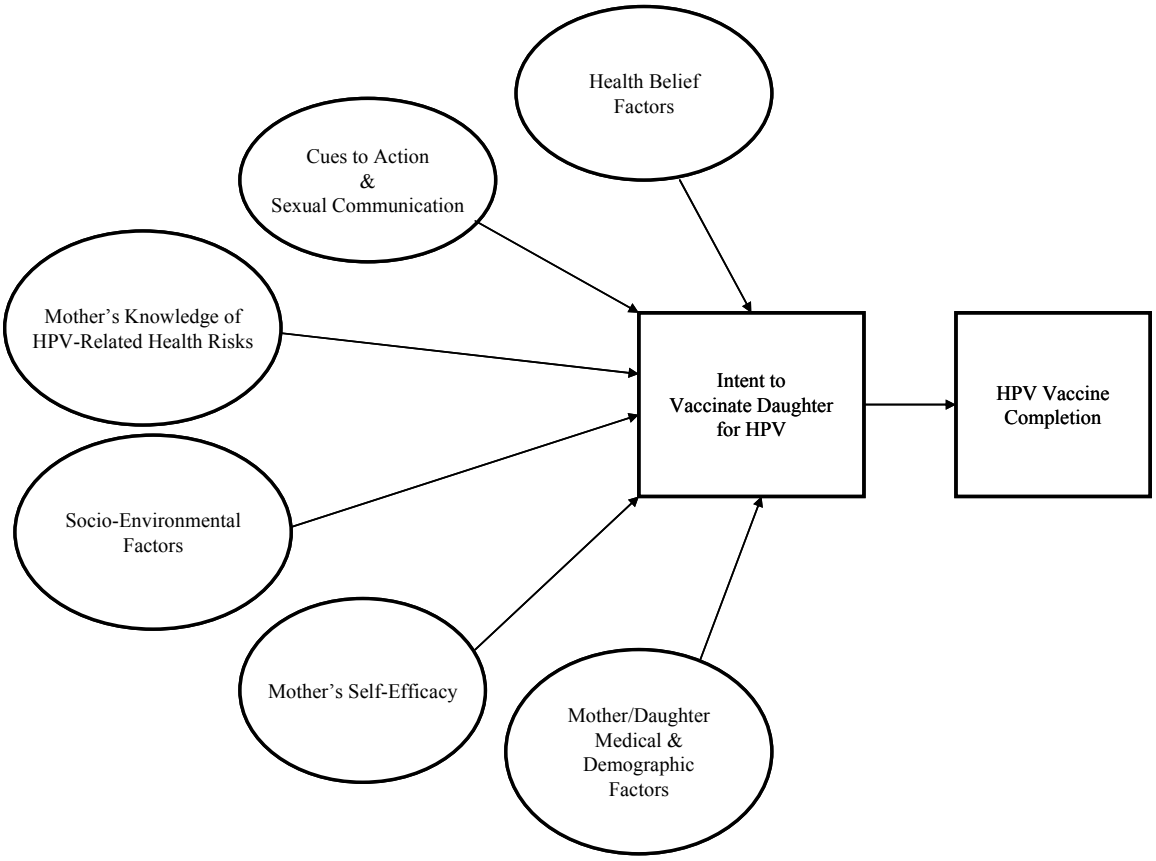

Figure 1. Proposed framework of factors influencing decision-making for HPV vaccination.

Appendix B

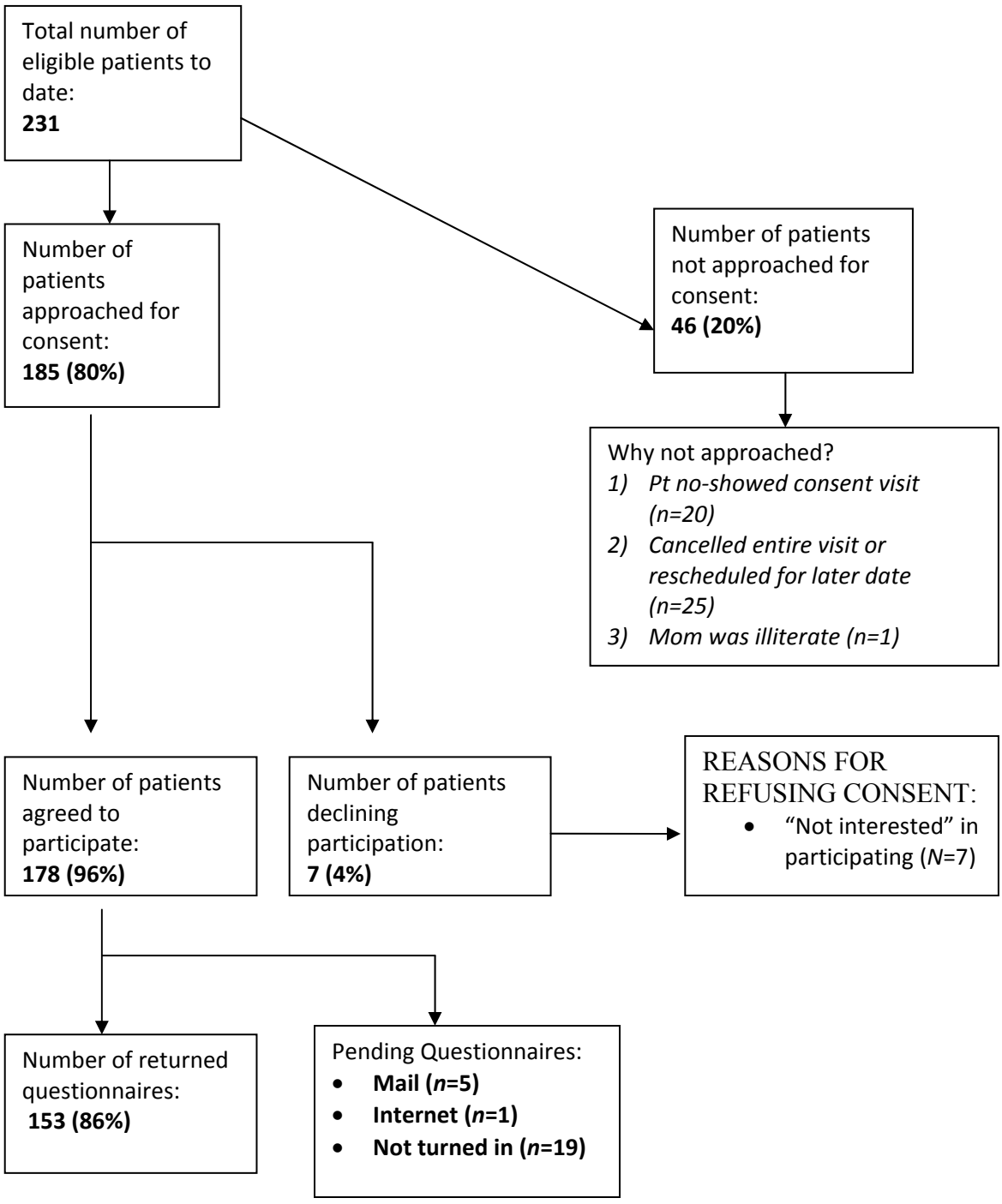

Figure 2. Enrollment report for mothers of childhood cancer survivors.

Appendix C

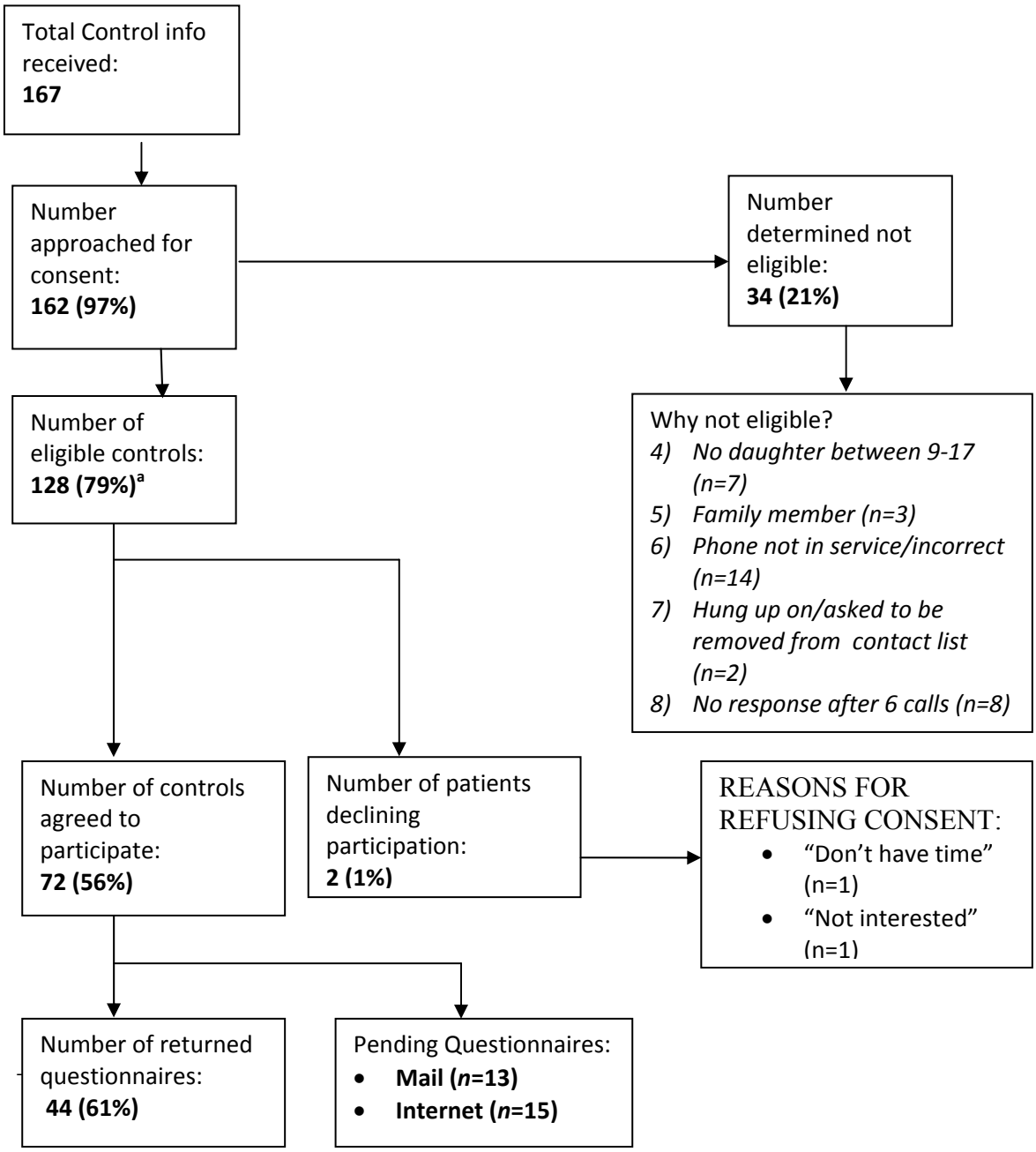

Figure 3. Enrollment report for mothers of healthy control daughters.

Note. [a] Fifty-four eligible controls pending due to on-going attempts to contact for participation in study.

Appendix D

Table 1

Variables Studied in HPV Questionnaire

Predictive factors	Location in questionnaire	Source or adapted source	# of items in scale
Health belief factors	pp. 71-73	Cox et al., 2010 Dempsey et al., 2006 Gerend et al., 2007 Kahn et al., 2008	Susceptibility: 5 Severity: 8 Barriers: 12 Benefits: 7
Mothers' self-efficacy	p. 73		6
HPV knowledge	pp. 67-68	Brabin et al., 2006 CDC, 2007b	10
Demographic & medical factors	pp. 65-66 pp. 78-80	Brabin et al., 2006 Constantine & Jerman, 2007 Dempsey et al., 2006 Rosenthal, et al., 2008	Demographic: 9 Maternal medical: 8 Daughter medical: 9

Vaccination status	p. 69		Maternal: 1 Daughter: 1
Vaccination intent	p.70	Constantine & Jerman, 2007	4

Appendix E

Table 2

Demographic characteristics of participants

Characteristic *M* (*SD*)	Mothers of Survivors *N* = 153	Mothers of Controls *N* = 44	Statistical test *p*-value
Maternal age	41.65 (7.04)	42.09 (6.71)	$t(195) = 0.37$, $p = 0.71$
Daughter age	13.33 (2.71)	13.36 (2.62)	$t(195) = 0.66$, $p = 0.95$
Maternal education	3.22 (1.41)	3.48 (1.13)	$t(184) = 1.07$, $p = 0.29$
Annual income	5.82 (4.33)	7.17 (4.12)	$t(182) = 1.78$, $p = 0.08$
HPV knowledge	6.04 (1.65)	6.43 (1.59)	$t(195) = 1.40$, $p = 0.16$
Susceptibility	11.82 (4.72)	9.61 (3.86)	$t(181) = -2.75^{*}$, $p = 0.007$
Severity	31.82 (5.25)	34.76 (4.78)	$t(181) = 3.25^{*}$, $p = 0.001$
Barriers	24.63 (5.92)	24.95 (6.44)	$t(176) = 0.31$, $p = 0.76$
Benefits	23.44 (4.21)	23.67 (4.36)	$t(178) = 0.32$, $p = 0.75$
Self-efficacy	25.78 (3.94)	26.51 (3.83)	$t(185) = 1.07$, $p = 0.29$
Vaccination intent	3.56 (1.80)	3.94 (2.03)	$t(118) = 0.96$, $p = 0.34$

Note. HPV = human papillomavirus.

Characteristics measured as continuous variables.

$^{*}p < .01$.

Appendix F

Table 3

Medical characteristics of participants

Characteristic *n* (%)	Mothers of Survivors *N* = 153	Mothers of Controls *N* = 44	Statistical test *p*-value
Ethnicity[a]			$\chi^2(1) = 4.25^*$
White	116 (75.8)	39 (88.6)	$p = 0.04$
Minority	36 (23.5)	4 (9.1)	
Marital status[b]			$\chi^2(2) = 4.57$
Married	109 (71.2)	36 (81.8)	$p = 0.10$
Wid/div/sep	22 (14.4)	7 (15.9)	
Other	21 (13.7)	1 (2.3)	
Vaccine status[c]			$\chi^2 (1) = 0.25$
Vaccinated	50 (32.7)	13 (29.5)	$p = 0.62$
Not vaccinated	99 (64.7)	31 (70.5)	
Annual Pap test[d]			$\chi^2(1) = 1.01$
Yes	105 (68.6)	35 (79.5)	$p = 0.31$
No	41 (26.8)	9 (20.5)	

(table continues)

Table 3 (continued)

Medical characteristics of participants

Characteristic *n* (%)	Mothers of Survivors *N* = 153	Mothers of Controls *N* = 44	Statistical test *p*-value
Abnormal Pap results[d]			$\chi^2(1) = 1.37$
Yes	60 (39.2)	22 (50.0)	$p = 0.24$
No	86 (56.2)	21 (47.7)	
STI[d]			$\chi^2(1) = .25$
Yes	22 (14.4)	8 (18.2)	$p = 0.62$
No	124 (81.0)	36 (81.8)	
HPV infection[d]			$\chi^2(1) = 0.001$
Yes	10 (6.5)	3 (6.8)	$p = 0.98$
No	128 (83.7)	39 (88.6)	
Cervical cancer[d]			$\chi^2(1) = 0.76$
Yes	8 (5.2)	1 (2.3)	$p = 0.38$
No	139 (90.8)	43 (97.7)	
Daughter received all immunizations[d]			$\chi^2(1) = 1.55$
Yes	141 (92.2)	44 (100)	$p = 0.21$
No	5 (3.3)	0 (0)	

(table continues)

Table 3 (continued)

Medical characteristics of participants

Characteristic *n* (%)	Mothers of Survivors *N* = 153	Mothers of Controls *N* = 44	Statistical test *p*-value
HPV rec by physician[d]			$\chi^2(1) = .000$
Yes	67 (43.8)	21 (47.7)	$p = 0.99$
No	73 (47.7)	23 (52.3)	

Note. STI = sexually transmitted infection; HPV = human papillomavirus; Rec = recommendation.

Characteristics measured as categorical variables.

[a]0 = *minority*, 1 = *white*; [b]0 = *widowed/divorced/separated*, 1 = *married*, 2 = *other*; [c]0 = *not vaccinated*, 1 = *initiated/completed vaccine series*, [d]0 = *no*, 1 = *yes*.

[*]$p < .05$.

Appendix G

Table 4

Correlations among Study Measures

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Intent													
2. Knowledge	-0.03												
3. Susceptibility	0.06	0.02											
4. Severity	0.29**	0.19	0.12										
5. Barriers	-0.34**	-0.15	0.05	-0.15									
6. Benefits	0.54**	0.14	0.02	0.25*	-0.48**								
7. Self-efficacy	0.25*	0.11	0.33**	0.40**	-0.39**	0.26*							
8. Annual Pap	0.02	-0.09	0.09	0.11	0.05	0.04	0.04						
9. Abnormal Pap results	0.19	-0.16	0.02	-0.04	-0.03	0.08	-0.19	0.13					
10. STI	-0.06	0.02	-0.00	0.08	0.22*	-0.31**	-0.06	0.07	0.14				
11. HPV infection	0.05	0.26*	0.10	-0.07	0.10	-0.01	-0.13	0.01	0.41**	0.08			
12. Cervical cancer	0.09	0.20	0.11	-0.17	0.13	-0.10	-0.05	-0.01	0.27*	0.07	0.47**		
13. Daughter immunizations	0.15	0.16	0.02	0.00	-0.09	-0.02	0.09	0.01	0.19	-0.07	0.08	0.05	
14. Physician rec HPV vacc	0.18	0.29*	-0.01	0.29**	-0.09	0.14	0.23*	-0.18	-0.12	0.38**	-0.03	-0.01	0.01

Note. $N = 84$. STI = sexually transmitted infection; HPV = human papillomavirus; Rec = recommendation; Vacc = vaccine.

*$p < .05$. **$p < .01$.

Appendix H

Table 5

Regression Analysis for Variables Predicting Intent to Vaccinate Daughter for HPV in the Future

Predictive factors	β	*t*	Sig. (*p*)
Group[a]	-0.14	-1.44	.15
Daughter's age	-0.18	-1.98	.05*
Perceived severity	0.12	1.08	.29
Perceived barriers	-0.09	-0.80	.43
Benefits	0.41	3.89	<.001**
Self-efficacy	0.05	0.42	.67

Note: $N = 84$

[a]0 = *mother of healthy control*, 1 = *mother of cancer survivor*.

*$p \leq .05$. **$p \leq .01$.

$R^2 = .374$

$F(6,77) = 7.67$, $p < .001$.

Appendix I

Human Papillomavirus (HPV) Vaccination Study

You are being invited to take part in a research study about a family's decision to have their daughters vaccinated against the virus that causes cervical and other cancers. This virus is known as the human papillomavirus or HPV. A goal of the study is to better understand what parents know about cervical cancer risk and what factors are important in their vaccination decisions.

As part of the study, you will be asked to fill out this questionnaire. Completion should take about 15 minutes.

It is entirely up to you whether you decide to take part in this study. If you decide not to take part in the study, this decision will not affect your daughter's care at St. Jude. If you decide to participate, please fill out the questionnaire on your own, in private. You are free to answer all, some, or none of the questions. You may feel some discomfort while answering some questions related to HPV, cervical cancer, and other women's health issues. Please remember that your answers will be kept private and will not be shared with your daughter's medical team. Do NOT put any additional information on the questionnaire (such as name, date of birth, home address, zip code, or phone number). Only the participant identification number will be used to link your responses with your daughter's medical information. After completing the questionnaire, place it in the attached envelope. Seal the envelope and give it to a member of our study team. If you are completing this questionnaire away from the St. Jude campus, please place the stamped self-addressed envelope into the mail. Thank you in advance for your consideration of this study.

Demographic Information

Date Form Completed: _____
(today's date)

Please answer the questions below. When lettered options are provided, please **circle** your response. When an answer line is provided, please **write in** your response.

1. How old are you (in years)? _____

2. What is your Race/Ethnicity? **(circle only one response)**

   1) Asian or Pacific Islander
   2) Black/African American
   3) Caucasian
   4) Hispanic/Latino
   5) Native American
   6) Middle Eastern
   7) Biracial or Multiracial - Please specify: _____
   8) Other - Please specify: _____

3. What is your current marital status?

   1) Married
   2) Widowed
   3) Divorced/separated
   4) Living with a partner, not married
   5) Single, never married, dating
   6) Single, never married, not dating
   7) Other - Please specify: _____

4. In terms of religious orientation, which group do you most closely identify with?

   1) Catholic
   2) Baptist
   3) Methodist
   4) Presbyterian
   5) Evangelical
   6) Jewish
   7) Mormon/Latter-Day Saints
   8) Muslim
   9) Hindu
   10) Buddhist
   11) Unitarian
   12) Agnostic
   13) Atheist
   14) Episcopalian
   15) Other - please specify: _____

5. Please indicate the number of years of education you have ***completed***.
   1) Grade school – last grade you completed: _____
   2) Some High School – last grade completed: _____
   3) High School Diploma or GED
   4) Some college – # of years in college: _____
   5) Bachelor's Degree
   6) Some graduate work – # of years post college: _____
   7) Graduate Degree
   8) Other - Please specify: _____

6. What was your annual **household** income last year?
   1) 0 - $9,999
   2) $10,000 - $19,999
   3) $20,000 - $29,999
   4) $30,000 - $39,999
   5) $40,000 - $49,999
   6) $50,000 - $59,999
   7) $60,000 - $69,999
   8) $70,000 - $79,999
   9) $80,000 - $89,999
   10) $90,000 - $99,999
   11) $100,000 - $109,999
   12) $110,000 - $119,999
   13) $120,000 - $129,999
   14) $130,000 - $139,999
   15) $140,000 - $149,999
   16) More than $150,000

You are a caregiver for a girl who is between 9 and 17 years old. For the remainder of this questionnaire, she will be referred to as your "daughter". If your daughter is followed in the ACT (survivorship) clinic, **please answer all questions about your daughter who is the St. Jude patient.** If you do not have a daughter seen in the ACT clinic at St. Jude, and you have more than one daughter between the ages of 9 and17, please answer all questions about your daughter who is closest in age to the St. Jude patient who referred you to this study.

7. What is your relationship to her? **(circle only one)**
   1) Biological Mother
   2) Stepmother
   3) Adoptive Mother
   4) Grandmother
   5) Aunt
   6) Foster Mother
   7) Other - Please specify: _____

8. How old is your daughter (in years)?: _____

9. What grade is your daughter in at school? _____

Knowledge

We would like to evaluate your current level of knowledge regarding specific health topics of importance to women and their families. Please circle the number of the correct response to each item below. If you are unsure about the correct answer, please give us your best guess. **Mark only one answer per question.**

1. The main job of a Pap smear is to screen for _____.

    1) Diabetes
    2) Ovarian cancer
    3) Heart disease
    4) Cervical cancer

2. _____ can cause abnormal Pap smear results.

    1) Increased caffeine
    2) HPV infection
    3) High cholesterol
    4) Urinary tract infection

3. Which of the following increases your chances for getting an HPV-related cancer?

    1) Smoking cigarettes
    2) Giving birth to many children
    3) Having first sex at a young age
    4) All of the above

4. Which of the following is associated with increased risk for Human Papillomavirus (HPV) infection?

    1) Having had multiple sexual partners
    2) Drinking after someone else
    3) Having sex more than once a day
    4) Engaging in same sex (e.g., gay or lesbian) activities

5. How common are HPV infections?

    1) Almost no one gets it, HPV is a very rare infection
    2) One-fourth of sexually active people contract HPV in their lifetime
    3) One-half of sexually active people contract HPV in their lifetime
    4) All sexually active people contract HPV during their lifetime

6. HPV is most common among women and men between the ages of _____.

1) 14 to 24 years
2) 25 to 35 years
3) 36 to 46 years
4) 47 to 57 years

7. How is HPV spread?

   1) Oral – genital contact
   2) Digital (finger) – genital contact
   3) Genital – genital contact
   4) All of the above

8. HPV is the main cause of _____.

   1) Pregnancy
   2) Genital warts
   3) Kidney stones
   4) Herpes

9. HPV infections can be cured by _____.

   1) Antibiotics
   2) Steroid shots
   3) Aspirin
   4) There is no cure for HPV infection.

10. Babies can get HPV in their _____ when born to HPV-infected mothers.

    1) Throats
    2) Muscles
    3) Eyes
    4) Feet

Vaccination and Vaccine Intent

Now we would like to continue asking you about health topics that are important to women and their families. There are no right or wrong answers to the following questions. We would like to know what ***you*** think about these important topics. Mark your response(s) to each item below.

1. Have you previously heard of **Gardasil** or **Cervarix,** the vaccines for Human Papillomavirus (HPV)?

   a) Yes
   b) No
   c) Not Sure

2. Where did you learn about the HPV vaccine? **(choose all that apply)**

   a) Never heard of the vaccine
   b) Friend
   c) Doctor
   d) Nurse
   e) School teacher
   f) Spouse
   g) Relative
   h) TV Commercials
   i) Internet
   j) Church
   k) Insurance company
   l) Other - Please specify: _____

1. Have you personally received the HPV vaccination (Gardasil or Cervarix)?

   1) Yes
   2) No
   3) Not Sure

2. Has your daughter received the HPV vaccination (Gardasil or Cervarix)? Mark only one answer.

   My daughter has received…
   1) 0 of the 3 shot series (has not started the vaccine)
   2) 1 of the 3 shot series
   3) 2 of the 3 shot series
   4) 3 of the 3 shot series (has completed the vaccine)

3. If your daughter has NOT already started the HPV vaccination series, please answer the following questions:

How likely is it that you will have your daughter…

	0 Definitely Will Not	1 Very Unlikely	2 Unlikely	3 Not Sure	4 Likely	5 Very Likely	6 Definitely Will
a. start the HPV vaccine within the next month?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
b. start the HPV vaccine within the next 6 months?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
c. start the HPV vaccine within the next 12 months?	**0**	**1**	**2**	**3**	**4**	**5**	**6**
d. vaccinated for HPV in the future?	**0**	**1**	**2**	**3**	**4**	**5**	**6**

Health Belief Factors

1. Please rate the likelihood of the following statements:

Compared to other girls her age, how likely is your daughter…

	1 Much Less Likely	2 Less Likely	3 Just as Likely	4 More Likely	5 Much More Likely
a. to get an HPV infection?	1	2	3	4	5
b. to have an abnormal Pap test?	1	2	3	4	5
c. to get cervical cancer?	1	2	3	4	5
d. to get a HPV-related cancer other than cervical cancer?	1	2	3	4	5
e. to die from cervical cancer?	1	2	3	4	5

2. Please rate how much you agree or disagree with the following statements:

	1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
a. HPV can cause cervical cancer.	1	2	3	4	5
b. Infection with HPV can lead to a serious illness.	1	2	3	4	5
c. HPV infection can cause genital warts.	1	2	3	4	5
d. Women can die from getting infected with HPV.	1	2	3	4	5
e. Treatment for cervical cancer is difficult.	1	2	3	4	5
f. Getting cervical cancer would affect my daughter's future (ability to have children, sexual functioning, disability).	1	2	3	4	5
g. Getting HPV would result in social consequences for my daughter (having to tell sexual partners, parents, health care workers, insurance companies, etc.)	1	2	3	4	5
h. Getting HPV would make it difficult for my daughter to get a husband/partner.	1	2	3	4	5

3. Please rate how much you agree or disagree with the following statements:

	1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
a. It would be hard for me to find the time to get my daughter vaccinated for HPV.	**1**	**2**	**3**	**4**	**5**
b. It would be hard for me to take my daughter to a clinic or doctor 3 times to get completely vaccinated for HPV.	**1**	**2**	**3**	**4**	**5**
c. It would be hard for me to get transportation to take my daughter for more than one appointment to get vaccinated for HPV.	**1**	**2**	**3**	**4**	**5**
d. It would be easy to take my daughter to the doctor's office to get the 3-shots of the HPV vaccine.	**1**	**2**	**3**	**4**	**5**
e. My daughter experiences pain when she receives a vaccination shot.	**1**	**2**	**3**	**4**	**5**
f. My daughter is in danger when she receives a vaccination shot.	**1**	**2**	**3**	**4**	**5**
g. The HPV vaccine would encourage my child to be more sexually active.	**1**	**2**	**3**	**4**	**5**
h. Not enough research has been completed on the safety of the HPV vaccine.	**1**	**2**	**3**	**4**	**5**
i. Not enough research has been completed on the effectiveness of the HPV vaccine.	**1**	**2**	**3**	**4**	**5**
j. I do not believe in vaccinations.	**1**	**2**	**3**	**4**	**5**
k. The HPV vaccine is expensive.	**1**	**2**	**3**	**4**	**5**
l. Having my daughter vaccinated for HPV is against my religious beliefs.	**1**	**2**	**3**	**4**	**5**

4. Please rate how much you agree or disagree with the following statements:

	1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
a. The HPV vaccine is very effective in preventing cervical cancer.	**1**	**2**	**3**	**4**	**5**
b. The HPV vaccine would greatly reduce the chance of getting cervical cancer.	**1**	**2**	**3**	**4**	**5**
c. The HPV vaccine is very safe.	**1**	**2**	**3**	**4**	**5**

d. The HPV vaccine is very risky.	**1**	**2**	**3**	**4**	**5**
e. Getting the HPV vaccine reduces worry about sexually transmitted infections.	**1**	**2**	**3**	**4**	**5**
f. Getting the HPV vaccine reduces worry about developing cervical and other HPV-related cancers.	**1**	**2**	**3**	**4**	**5**
g. Getting my daughter the HPV vaccine did/would help me to feel like a good parent.	**1**	**2**	**3**	**4**	**5**

Please rate how much you agree or disagree with the following statements:

Regardless of the decisions I make/ or have made about HPV vaccination, I believe that I could…

	1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
1. talk with my daughter's doctor about this issue.	**1**	**2**	**3**	**4**	**5**
2. discuss this vaccine with my daughter.	**1**	**2**	**3**	**4**	**5**
3. discuss this vaccine with my spouse/partner.	**1**	**2**	**3**	**4**	**5**
4. pay (or get insurance to pay) for the vaccine.	**1**	**2**	**3**	**4**	**5**
5. get my daughter to the medical clinic.	**1**	**2**	**3**	**4**	**5**
6. successfully negotiate completion of the HPV vaccination with my daughter.	**1**	**2**	**3**	**4**	**5**

Are there other things which did/would influence your ability to get your daughter vaccinated for HPV? If so, what?

_____
_____
_____
_____

Social and Environmental Influences on Decisions

There are new vaccines that protect against HPV types that cause most cervical cancers. Some families decide to have their adolescent daughters vaccinated, while others decide not to. The choice for each family is personal and many different things may influence the decision. Please answer the following questions so we can better understand how the decision to vaccinate for HPV is made.

Please answer the following items regardless of whether or not your daughter has been vaccinated. Please rate how important the following factors were/would be in making HPV vaccine decisions for your daughter:

	1 Very Unimportant	2 Unimportant	3 Neither Important nor Unimportant	4 Important	5 Very Important
1. Physician recommendation	1	2	3	4	5
2. TV commercials/media	1	2	3	4	5
3. Family history of abnormal Pap smears	1	2	3	4	5
4. You or anyone close to you having experienced genital warts	1	2	3	4	5
5. Family history of cervical cancer	1	2	3	4	5
6. Family history of cancer in general	1	2	3	4	5
7. You or anyone close to you having experienced a sexually transmitted infection	1	2	3	4	5
8. Your friends' approval of the HPV vaccine	1	2	3	4	5
9. Your friends having their daughters vaccinated for HPV	1	2	3	4	5
10. Required for school enrollment	1	2	3	4	5
11. Spouse/significant other's approval of the HPV vaccine	1	2	3	4	5
12. Your religious beliefs	1	2	3	4	5
13. Insurance coverage/cost	1	2	3	4	5
14. Other (please specify): _____ _____	1	2	3	4	5

_____					

1. Does your health insurance cover the HPV vaccination?
    1) Yes
    2) No
    3) Not Sure
    4) I do not have health insurance

2. What else would influence your decision to vaccinate your daughter against HPV?

    _____

    _____

    _____

    _____

1. Please rate how much you agree or disagree with the following statements:

Who should make the decision to have your daughter vaccinated for HPV?

	1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
a. Mother only	**1**	**2**	**3**	**4**	**5**
b. Father/spouse/partner only	**1**	**2**	**3**	**4**	**5**
c. Daughter only	**1**	**2**	**3**	**4**	**5**
d. Parents decide without daughter's input	**1**	**2**	**3**	**4**	**5**
e. Parents decide with daughter's input	**1**	**2**	**3**	**4**	**5**
f. Doctors should decide	**1**	**2**	**3**	**4**	**5**
g. Schools should decide	**1**	**2**	**3**	**4**	**5**
h. Government should decide	**1**	**2**	**3**	**4**	**5**
i. Church should decide	**1**	**2**	**3**	**4**	**5**
j. Other - Please specify: _____ _____	**1**	**2**	**3**	**4**	**5**

Medical Background

As girls mature, they may begin to visit a doctor specializing in the female reproductive system. This type of doctor is known as a "gynecologist" or an "obstetrician/gynecologist," sometimes known as an OB/GYN. There are many reasons why females visit these doctors, and by filling out this section, you will help us estimate how many women are getting screened/tested for cervical cancer, how often screening/testing is taking place, and even the results of screening/testing. By knowing this information, we can maximize our chances to help women stay healthy in the future.

The following questions are about **YOUR** personal medical history. Please circle your item responses below.

1. Have you ever been to an obstetrician/gynecologist (OB/GYN)?
   1) Yes
   2) No
   3) Not Sure

2. Have you ever gotten a mammogram?
   1) Yes
   2) No
   3) Not Sure

3. Do you get a Pap test every year?
   1) Yes
   2) No
   3) Not Sure

4. Have you ever had an abnormal Pap test result?
   1) Yes
   2) No
   3) Not Sure

5. Have you ever had a sexually transmitted infection (STI)?
   1) Yes
   2) No
   3) Not Sure

6. Have you ever had an HPV infection?
   1) Yes
   2) No
   3) Not Sure

7. Have you ever had cervical cancer?
   1) Yes
   2) No

3) Not Sure

8. Have you ever had a Pap smear?
   1) Yes – approximate date of last Pap smear (month/year): _____. At what age did you get your first Pap smear? _____
   2) No
   3) Not Sure

The following questions are about **YOUR DAUGHTER'S** medical history. Please circle your item responses below.

9. In the last year, how often has your daughter seen her **primary care physician/pediatrician?** (Do not include your family's ACT/survivorship clinic visit in this total).
   1) None
   2) 1 to 2 times
   3) 3 to 5 times
   4) 6 to 10 times a year
   5) More than 10 times
   6) Other - Please specify: _____

10. Has your daughter received all recommended childhood vaccinations?
    1) Yes
    2) No
    3) Not Sure

11. Has your daughter ever been to a gynecologist (GYN)?
    1) Yes
    2) No
    3) Not Sure

12. Has your daughter ever had a Pap smear?
    1) Yes – approximate date of last Pap smear (month/year): _____. Age at which your daughter received first Pap smear: _____
    2) No
    3) Not Sure

13. Does your daughter get a Pap test every year?
    1) Yes
    2) No
    3) Not Sure

14. Has your daughter ever had an abnormal Pap test result?
    1) Yes
    2) No

3) Not Sure

15. Has your daughter ever had a sexually transmitted infection (STI)?
    1) Yes
    2) No
    3) Not Sure

16. Has your daughter ever been diagnosed with an HPV (Human Papillomavirus) infection?
    1) Yes
    2) No
    3) Not Sure

17. Has your daughter's doctor ever recommended that she receive the HPV vaccine?
    1) Yes
    2) No
    3) Not Sure

Please answer the following questions about your daughter:			
	1 Yes	**2 No**	**3 Not Sure**
1. My daughter is allowed to date.	**1**	**2**	**3**
2. My daughter currently has a boyfriend or is in a committed relationship.	**1**	**2**	**3**
3. My daughter does not have a current boyfriend and is not in a committed relationship, but she has been in the past.	**1**	**2**	**3**
4. My daughter is currently sexually active.	**1**	**2**	**3**
5. My daughter is not currently sexually active, but she has been in the past.	**1**	**2**	**3**
6. My daughter is not currently sexually active, but I anticipate that she will be sexually active before she completes high school.	**1**	**2**	**3**

Maternal-Adolescent Communication

As girls grow up, mothers may talk with their daughters about ways to keep healthy and safe. Different messages about physical development and sexuality are provided at different times in a girl's life. Please answer the following questions so that we can learn more about how and when these discussions take place.

	1 Strongly Disagree	2 Disagree	3 Uncertain	4 Agree	5 Strongly Agree
1. I try to see my child's point of view when we talk about sex and sexuality.	**1**	**2**	**3**	**4**	**5**
2. I talk with my child about HIV.	**1**	**2**	**3**	**4**	**5**
3. I talk with my child about preventing pregnancy.	**1**	**2**	**3**	**4**	**5**
4. I set rules for my child about sex and sexuality.	**1**	**2**	**3**	**4**	**5**
5. I talk with my child about using condoms.	**1**	**2**	**3**	**4**	**5**
6. I talk with my child about body changes that happen in adolescence.	**1**	**2**	**3**	**4**	**5**
7. I talk with my child about sexually transmitted illnesses.	**1**	**2**	**3**	**4**	**5**
8. I encourage my child to ask questions about sex and sexuality.	**1**	**2**	**3**	**4**	**5**
9. I think girls should learn about sex before they start their period.	**1**	**2**	**3**	**4**	**5**
10. I think it's important to wait until girls are emotionally ready to talk about sex.	**1**	**2**	**3**	**4**	**5**
11. I think it's important to wait until girls are physically mature to talk about sex.	**1**	**2**	**3**	**4**	**5**
12. I talk with my child about sex and sexuality when I think her friends are becoming sexually active.	**1**	**2**	**3**	**4**	**5**
13. I talk with my child about sex any time my child asks me questions.	**1**	**2**	**3**	**4**	**5**

14. I talk with my child about sex and sexuality when I think she is becoming sexually active.	**1**	**2**	**3**	**4**	**5**
15. I talk with my child about sex and sexuality before she is going out with friends.	**1**	**2**	**3**	**4**	**5**
16. I use my own experiences when I talk to my child about sex and sexuality.	**1**	**2**	**3**	**4**	**5**
17. I expect my child to follow rules that I set about sex and sexuality.	**1**	**2**	**3**	**4**	**5**
18. I let my child talk as much as I do when we discuss sex and sexuality.	**1**	**2**	**3**	**4**	**5**

HPV Communication

2. Please rate the following statements about discussing the HPV vaccine with your daughter:

Regarding the HPV vaccine, I have told/will tell my daughter…

	1 Untrue	2 Somewhat Untrue	3 Somewhat True	4 True
a. Nothing	**1**	**2**	**3**	**4**
b. It is a shot to keep girls healthy	**1**	**2**	**3**	**4**
c. It is a shot to protect girls from cervical cancer	**1**	**2**	**3**	**4**
d. It is a shot to protect girls from HPV	**1**	**2**	**3**	**4**
e. Other - Please specify: _____ _____	**1**	**2**	**3**	**4**

Please answer the following questions.

1. Currently, adolescent girls can legally receive HPV vaccination without parental permission/consent.
   1) Yes
   2) No
   3) Not Sure

2. Adolescent girls should be allowed to seek HPV vaccination without parental permission/consent.
   1) Yes
   2) No
   3) Not Sure

3. Information about the HPV vaccine should be made available to adolescent girls.
   1) Yes
   2) No
   3) Not Sure

4. Who should provide information to adolescent girls about HPV vaccination? **(choose all that apply)**
   1) Parents
   2) Physician/pediatrician
   3) Gynecologist
   4) School nurse
   5) Health class teachers at school
   6) Friends
   7) Community health center
   8) TV Advertisements

9) Other - Please specify: _____
10) I do not think adolescent girls should be provided with information about HPV vaccination.

Would you be interested in learning about future St. Jude studies which could include the free administration of the HPV vaccine? Please check one response below.

_____ Yes
_____ No
_____ Unsure

You are finished with this questionnaire. Thank you for your participation. Your answers to these questions will help us to better understand how parents make decisions regarding whether to vaccinate their daughters against cervical and other HPV-related cancers. Please contact Dr. James Klosky at 901-595-4128 if you have any questions about this study. Thank you again for participating!

Appendix J

Information Sheet for

Human Papillomavirus (HPV) Vaccination among Survivors of Childhood Cancer Study

You participated in a research study about a family's decision to have their daughters vaccinated against HPV, the virus that causes cervical cancer. A goal of the study is to better understand what parents know about cervical cancer risk and what factors are important in their vaccination decisions. The research staff is sending you this information sheet to provide you with more information regarding HPV vaccination among survivors of childhood cancer.

What is HPV?

Genital human papillomavirus (HPV) is the most common sexually transmitted infection and approximately 50–70% of sexually active women contract HPV at some point during their lifetime. Any sexually active person - no matter what race, gender, or sexual orientation - can get HPV. HPV infection rates are highest in younger women and rise sharply soon after the median age of first sexual activity (which is about 16.9 years for females). Specifically, the prevalence of HPV has been estimated to be as high as 39.6% among 14- to 19-year olds and 49.3% among 20- to 24-year old sexually active females.

What are the symptoms of HPV and health consequences?

Some HPV infections may be asymptomatic and other HPV infections can cause genital warts in men and women. Although most HPV infections are transient (i.e., will

resolve on their own within 1 to 2 years), persistent HPV infection is a necessary cause of cervical cancer because 100% of cervical cancers are HPV related. Women are screened for cervical cancer with Papanicolaou (Pap) testing to identify abnormal cells in the cervix that may lead to cancer.

There are over 100 types of HPV, and approximately 40 strains affect the genital tract. Oncogenic HPV strains have been linked to cervical, vaginal, vulvar, penile, and anal cancers. Cervical cancer is the second most common cancer among women worldwide and is the leading cause of cancer-related deaths among women in developing countries. In particular, HPV types 16 and 18 are responsible for 70% of cervical cancers. The slow progression of abnormal cell growth due to HPV infection leading to cervical cancer is estimated take 10 to 15 years. Therefore, although HPV occurs most often in sexually-active adolescents and women between the ages of 15 and 24, cervical cancer diagnosis most often occurs in women over the age of 40, with median age at diagnosis being 48 years.

How do people get genital HPV infections?

HPV is spread through direct skin-to-skin contact during vaginal, anal, or oral sex with someone who has been infected with HPV. This can include oral-genital, finger-genital, and genital-genital contact. A woman is at greater risk for getting HPV-related cancers if she smokes cigarettes, began having sex at an early age, has had multiple sexual partners, does not use condoms, and/or has given birth to many children. On rare occasions, mothers can transmit HPV infections to a newborn during delivery, which can cause dangerous warts in the infant's throat.

Can HPV be treated?

No. There is no cure for HPV. Most genital HPV infections go away as the body's immune system clears the infection. Ninety percent of HPV infections go away (or are cleared from the body) within 2 years. Although the HPV infection itself cannot be treated, genital warts can be removed with medications or treatments from a physician. Additionally, if a Pap test reveals precancerous cells in the cervix, this can and should be addressed immediately.

Can HPV be prevented?

Yes! The only sure way to prevent HPV is to abstain from any sexual activity. Condoms can provide some, but not total, protection against HPV as condoms do not cover the entire genital area. Recently, two vaccines to protect adolescents from HPV have been developed: Gardasil (Merck & Co.) and Cervarix (GlaxoSmithKline). They are currently available and have been demonstrated to be very safe and clinically effective.

The Advisory Committee on Immunization Practices (the committee that develops written recommendations for the routine administration of vaccines to children and adults) recommends routine HPV vaccination for ***all*** females aged 11-12 years with 3 doses of the quadrivalent (Gardasil) or bivalent (Cervarix) HPV vaccine. The vaccine can even be started as young as 9 years-of-age (Gardasil) or 10 years-of-age (Cervarix). The American Cancer Society guidelines also recommend routine HPV vaccination for ***all*** girls ages 11 to 12 and as early as 9 at the discretion of doctors.

Why is HPV vaccination important for childhood cancer survivors?

Some cancer survivors may have impaired immune systems as a result of their cancer treatment. And since we rely on our immune systems to clear HPV once infected,

those with depressed immune function are at greatest risk for HPV-related complications. As a result, the Children's Oncology Group has developed *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancer*, which serve as the gold standard in the screening for late effects that may arise due to treatment of pediatric cancer. These guidelines recommend HPV vaccination for all eligible females surviving childhood cancer.

For more information visit these websites:

American Cancer Society website on HPV vaccination

http://www.cancer.org/docroot/cri/content/cri_2_6x_acs_recommendations_for_hpv_vaccine_use_to_prevent_cervical_cancer_and_pre-cancers_8.asp

Centers for Disease Control and Prevention website on HPV

http://www.cdc.gov/STD/HPV/STDFact-HPV.htm#Whatis

Thank you again for participating in our study. If you have further questions concerning this project, please call Dr. James Klosky at 901-595-3581.