

EMERGING ADULT AND YOUNG ADULT CANCER SURVIVORS:  
EXPLORING COPING, PARENTAL CARE AND CONTROL, AND SPIRITUALITY

by

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November, 2015

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Due to medical advances and higher success rates in cancer treatments, more emerging and young adults live with this chronic condition. However, how this population copes with cancer is understudied, therefore the current study investigates coping strategies in this population. Two hundred and ten emerging and young adult cancer survivors recruited from online social media sites completed an online survey and reported on their coping strategies, perception of parental attitudes, spiritual beliefs, and open-ended coping questions. While many participants use different behaviors in their coping with cancer, approximately 48% of participants reported to cope adaptively highly using “acceptance”, “humor”, “positive reframing”, and “active coping”. Thirty-five percent of participants reported to cope maladaptively with high use of “distraction” and “self-blame” behaviors in their coping strategies.

Correlation analysis revealed many significant associations between study variables, highlighting the importance of both Maternal and Paternal Care and perception of Maternal Control in coping. The regression analysis indicated that older age, recent treatment, higher

levels of perceived parental care, and higher emphasis on spirituality were predictive of adaptive coping in this population. Practical implications and recommendations for clinicians and health professionals working with emerging and young adult cancer survivors are discussed.

Keywords: *emerging adults, young adults, cancer, coping, parental care and control, and spirituality*



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A Thesis

Presented To the Faculty of the Department of Human Development and Family Science  
East Carolina University

In Partial Fulfillment of the Requirements for the Degree of  
Masters of Science in Child Development and Family Relations

by

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November 2015

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## **DEDICATION**

I would like to dedicate my thesis to my wonderful mother, Martina and my courageous nephew, Jason. Your strength, courage, and faith throughout your cancer journeys has amazed and inspired me. Also, I would like to dedicate my thesis to your bone marrow donors, my aunt Sue Ann and my niece, Jessica. Thank you for selflessly giving to make their journeys possible.

## **ACKNOWLEDGEMENTS**

This thesis would not have been possible without the help of many people. I would first like to express my deepest gratitude to Dr. Natalia Sira. I have truly valued and appreciated your encouragement, support, and mentorship. Thank you for helping me become a better researcher. I would also like to thank my committee members, Dr. Lisa Campbell and Dr. Angela Lamson, for their time, patience, and understanding throughout this process.

I greatly appreciate my mother for giving me roots to come home and wings to help me explore my passions and interests. Your love and support has been instrumental in my graduate career. I would also like to thank my brother and sister for their continuous encouragement and support. I would like to thank Elizabeth Nunn for always being there when I needed to be reminded to have hope. Finally, I would like to give a special thanks to Chase Martin for encouraging me and helping me stay positive throughout this journey.

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## **CHAPTER 1: INTRODUCTION**

One out of every 530 young adults (20-39 years old) is a survivor of childhood cancer (Ward, DeSantis, Robbins, Kohler & Jemal, 2014). It is estimated between 60,000 and 70,000 additional adolescents and young adults (15-39 years old) are diagnosed with cancer each year (American Cancer Society, 2014; National Cancer Institute, 2015). Although, cancer is more prominent in adolescents and young adults there is more research being conducted with pediatric oncology patients (i.e. young children) (Bleyer, 2007). There is sparse research available on how young adult cancer survivors cope with these challenges (Rabin, Horowitz & Marcus, 2013). Thus, the current study investigates how emerging and young adult cope by using the Double ABCX model as a framework to examine how stressors, resources, and perceptions contribute to bonadaptation (adaptive coping) or maladaptation (maladaptive coping).

While cancer presents many challenges and uncertainties to individuals of any age, for young adults the cancer diagnosis presents additional stressors related to cancer, which are current developmental challenges (Kent et al., 2012). Developmentally, young adults are in the beginning stages of developing identities, forming relationships with peers and romantic partners, and pursuing educational or career goals (Arnett, 2007; Berk, 2008). For young adults, the cancer diagnosis is a disruption in their life plans and may halt their ability to become independent from their family (Corbeil, Laizner, Hunter, & Hutchinson, 2009; Millar, Patterson & Desille, 2010).

Although most of their peers are becoming independent from their families, the young adult with cancer often becomes more dependent upon their parents and family for support and financial assistance during cancer treatments (Kent et al., 2012). At the same time, parents can

be more than just a financial resource for a young adult with cancer. They can be a support system that can help the young adult cope and adjust to cancer (Foster et al., 2011; Howard et al., 2014; Kumar & Schapira, 2013; Orbuch, Parry, Chesler, Fritz & Repetto, 2005).

Young adult survivors perception of their parents as a support system begins in early childhood. The child's relationship formed with parents is based on their early childhood interactions with parents, where parents provided care for the child (Bowlby, 1969). The care experienced by the child could have been positive (emotionally supportive, nurturing, affectionate) or negative (rejecting, neglecting, ignoring) (Schafer, 1965). Positive parent-child relationships foster the development of self-competence and emotional comfort (Archibald, Graber & Brooks-Gunn, 1999; Armsden & Greenberg, 1987). Parental relationships with higher parental control can be seen as manipulative and limiting the child's ability to become independent (Schafer, 1965). Additionally, parental care and control are important aspects in the formation and perception of parent-child relationship (Bowlby, 1969; Schaefer, 1965) and this relationship is found to be associated with coping (Foster et al., 2011; Howard et al., 2014; Kumar & Schapira, 2013; Orbuch et al., 2005). In addition to an individual's perception of parental relationships as a source of competence and strength, a person's spiritual beliefs have been found to be a resource for coping with cancer (Lima et al., 2013; Puchalski, 2012; Schendier & Mannell, 2006; Sira, Desai, Sullivan & Hannon, 2014; Speraw, 2006).

Often, the life-threatening nature of cancer may lead an individual to question spiritual beliefs (Dyer, 2011). It was reported that for some individuals, the stress of diagnosis may cause them to depend upon their spiritual beliefs to cope (Puchalski, 2012). Previous research have indicated that individuals who have reported using their spiritual beliefs, as a tool in coping reported using positive/adaptive coping mechanisms (Lima et al., 2013; Schendier & Mannell,

2006; Sira et al., 2014; Speraw, 2006). Throughout the cancer trajectory, individuals with stronger spiritual beliefs are able to reflect and put into perspective what they value as important in life and their purpose in life (Lima et al., 2013; Puchalski, 2012; Sira et al., 2014).

Individuals diagnosed with cancer face a lifetime of challenges after treatments, whether these are the late physical side effects of treatments or emotional stressors such as fear of relapse (Ward et al., 2014). Therefore, the purpose of this study is to explore the overall coping strategies of young adults to these challenges, investigate the contribution of perceived parental care and control aspects on coping ability and examine the use of spirituality as a coping tool in this population. The Double ABCX Model is used in the study to explain the uniqueness of young adult cancer stressors/demands when dealing with cancer, how the resources (perceived parental care and control and spiritual beliefs), and the perception of cancer (based on perceptions of resources) may contribute to the outcome of adaptive or maladaptive coping with cancer.

## **Summary**

The purpose of the study is to investigate the contribution of internal resources (perceived parental care and control) and spirituality to coping. Emerging adult and young adult cancer survivors are challenged with cancer-associated stressors in addition to developmental stressors/tasks. Medical and technological advances have lead to more young adults facing these challenges however knowledge on coping within these populations is limited (Rabin et al., 2013). Thus, due to chronic nature of cancer, there is a need to better understand internal/individual resources that may contribute to adaptive and maladaptive coping in this population, to be able to recognize maladaptive coping behaviors and promote adaptive coping behaviors.

## **CHAPTER 2: THEORECTICAL FRAMEWORK**

Within this chapter, the Double ABCX Model explains the unique stressors/demands placed upon the young adult and contributing factors to individual's adaptive coping or maladaptive coping. The theoretical framework also demonstrates the complexity of coping. Utilizing the Double ABCX model enables the researcher to understand how important variables (stressors, resources, perceptions) interactions contribute to either adaptive or maladaptive coping during cancer survivorship.

### **The Double ABCX Model**

The diagnosis, long treatments, and survivorship provide unique stressors for individuals with cancer and their families. The Double ABCX model specifies a structure for how families adapt and adjust to stressors, expressing the unique factors contributing to the different outcomes for families and individuals challenged with similar stressors (McCubbin & Patterson, 1983; Patterson, 1988). The ABCX model describes (a) an event or stressor taking place within the family system (McCubbin & Patterson, 1983). The family has to find a way to manage the events that are either normative life events (getting married, having a child, a new job, etc.) or non-normative life events (sudden illness or death) (Lavee, McCubbin, & Olson, 1987; Patterson, 1988). Based on this model, the family then has to (b) assess their available resources to deal with the new demand placed upon them (McCubbin & Patterson, 1983). Examples of resources for young adults may be support from family members, peers, and other support available such as religious organizations. An appraisal of available resources will lead the family to (c) a definition/perception of the stressor (McCubbin & Patterson, 1983). This perception is the result of perceived available resources, previous experiences with stressors, and

how they have adapted to previous stressors (McCubbin & Patterson, 1983). The perception of the stressor and resources available to the individual and family determine whether family enters into (x) a state of crisis or return to a state of stability/normalcy (McCubbin & Patterson, 1983).

After entering into the state of crisis, the Double ABCX model considers additional factors contributing to family adaptation. Family crises evolve and resolve with time (McCubbin & Patterson, 1983). In particular after major family crises (i.e. death, family role changes, natural disasters), families may experience (aA) multiple stressors (pile-up of stressors) (McCubbin & Patterson, 1983). These stressors may emerge from individual family members, the family system, or the community of the individual and family (McCubbin & Patterson, 1983). Pile-up stressors can be related to the initial stressor, normal life transitions, previous strains/demands on the family, the result of family attempts to cope, or uncertainty in the family or societal expectations for adaptation (McCubbin & Patterson, 1983).

The ability to manage pile-up stressors will result from (bB) resources of the individual or family (McCubbin & Patterson, 1983). There are two types of resources, pre-existing family resources or expanded family resources (McCubbin & Patterson, 1983). Existing resources are strengthened or developed from the initial crisis or pile-up of demands (McCubbin & Patterson, 1983). Finally, the family will assign (cC) an overall definition and meaning is assigned to the crisis, encompassing the initial stressor, pile-up stressors, resources (existing and expanded) and thoughts about what actions need to be taken to return the family to normalcy/balance (McCubbin & Patterson, 1983). The definition and meaning assigned by the family will contribute to the family's ability to cope (McCubbin & Patterson, 1983). Family coping is result of the interactions between family resources, perceptions, and responses to multiple stressors after the initial crisis (McCubbin & Patterson, 1983). How the family is able to cope will

contribute to (xX), which is the family's ability to adapt/adjust (McCubbin & Patterson, 1983). Family adaptation/adjustment investigates the ability of the individual family member to fit into the family system and the family's ability to fit in the surrounding social community (McCubbin & Patterson, 1983). The outcome of this fit is described along a continuum of outcomes, with the positive end as "*Bonadaptation*" (balance is achieved) and the negative end as "*Maladaptation*" (imbalance) (McCubbin & Patterson, 1983, p. 20).

## **Summary**

In the current study, the Double ABCX model is used to provide a framework for the coping process. Components of the Double ABCX model are used to understand stressors related to cancer, resources (paternal care/control and spirituality), and individual perceptions of parental care and control and spirituality that will contribute to coping strategies. Bonadaptation (adaptive coping behaviors) or Maladaptation (maladaptive coping behaviors) is the outcome, which is based on the interactions of stressors, resources, and perception.

## **CHAPTER 3: LITERATURE REVIEW**

Young adult cancer survivors often expect to return to the life they had before cancer, however often times they are unable to return to their previous lifestyles because of side effects from cancer treatments (fatigue, pain, anxiety, depression) (Hauken, Laresen & Holsen, 2013). The Double ABCX Model provides insight into how young adults may or may not be able to adapt and cope with cancer and their new altered lifestyles. This chapter will begin with examining the stressors/demands presented to young adult cancer survivors and then explore the coping strategies used by this population. After examining the demands and coping strategies of adult survivors, the literature will examine young adult relationships with parents, peers, and spirituality as potential factors contributing to adaptive or maladaptive coping.

### **Stressors For Young Adult Cancer Survivors**

The Double ABCX model suggests that adjustment/adaptation to major life crises takes time, and as a result the individual is challenged with multiple stressors (McCubbin & Patterson, 1983). Emerging adult (18-30) cancer survivors are confronted with more developmental challenges (normal life transitions) than young adults (31-40). During emerging adulthood, there are no limitations on where and what emerging adult can do because there are no strict roles in place, emerging adults can freely explore all the possibilities life has to offer (Arnett, 2000). Developmentally, emerging adults are in a stage where they expected to plan for the future, explore career and educational opportunities, form romantic relationships, establish self-identity and become independent from their families (Arnett, 2007; Berk, 2008). Young adulthood is established when young adult has become financially independent, self-sufficient, able to take responsibilities for actions, and make decisions (Arnett, 2000).

The individual continues to develop as person throughout cancer treatments (Morgan, Davies, Palmer, & Plaster, 2010). It has been reported that the survivor's development can be altered by cancer treatments, in part because the individual may lack personal resources or social support, have concerns about the future, new physical limitations, or lack self-esteem (Bauld, Anderson & Arnold, 1998; D'Agnostino, Penney & Zebrack, 2011). At the same time, young adults are also challenged with the social and peer isolation experienced during treatments, changes in body image, the strains or interruptions placed upon educational goals and/or relationships affect the identity formation and sexual development of this age group (Epelman, 2013; Morgan et al., 2010). Adolescents and adults, who experience illness or disabilities, are more likely to be effected by stressors of illness because they have defined expectations of themselves and a sense of identity formed compared to children, who are forming their identities, and thus, easily alter self-concepts to include this change (Joubert et al., 2001).

Researchers have found that young adult cancer survivors, who did not fit in with peer groups or did not reach social milestones (graduating, marriage, children, etc.), experienced social isolation (Howard et al., 2014). Survivors reported feeling uncertain in their ability to continue on with their previous life plans or goals (Corbeil et al., 2009). Researchers have reported that survivors' feelings of uncertainty toward their future are a primary reason for their inability to plan and participate in normal life events (Corbeil et al., 2009; Decker, Haase & Bell, 2007).

**Uncertainty.** It was reported that the survivor's future is full of uncertainty and fear of cancer reoccurring (Baker, Denniston & Smith, 2005; Corbeil et al., 2009; Decker et al., 2007). Fear of relapse and uncertainty in cancer are emotional and psychological stressors for survivors (Baker et al., 2005). Survivors experience different degrees of uncertainty throughout the cancer

treatments and treatment outcomes (Corbeil et al., 2009; Decker et al., 2007). Uncertainty is a part of cancer experience because the nature of cancer is a source of uncertainty with regards to effectiveness of treatments, the possibility of relapse, and lack of knowledge/understanding of cancer (Corbeil et al., 2009). The end of cancer treatments often results in survivors entering into a state of emotional distress due to these new uncertainties relating to the future (Langeveld & Arbuckle, 2008).

**Future plans.** Researchers have found that young adult cancer survivors often have to evaluate and restructure their future life plans in particular their academic and career plans (D’Agnostino et al., 2011; Millar et al., 2010). The individual’s lifestyle is also different than their lifestyle before cancer diagnosis because of the late side effects of cancer treatments on the individual (Hauken et al., 2013). The cancer diagnosis affect the normal life trajectory for these individuals, such as graduating, setting career goals to further education, attending social events like high school graduation and prom, getting married, and having children (Burgoyne et al., 2015; Kent et al., 2012).

Researchers have reported that young adult survivors may experience new emotional stressors related to cancer effects such as fertility issues and facing their mortality (Langeveld & Arbuckle, 2008). Often the stressors are presented after cancer because the individual did not have time or energy to focus on or think about these concerns during treatment (Langeveld & Arbuckle, 2008). Additionally, after ending cancer treatments, many young survivors have expressed worry over the cancer reoccurring (Decker et al., 2007; Garofalo, Choppala, Hamann, Gjerde, 2009; Kent et al., 2012; Roberts et al., 1997). Many survivors are challenged to find meaning behind their cancer experience, to configure a new identity, to deal with the anxieties

directly related to facing their own mortality, and other emotional issues such as loneliness (Millar et al., 2010).

**Family and peer relations.** Not only are young adults forced to re-evaluate their future life plans but they are navigating new challenges and changes to current relationships within their lives (Langeveld & Arbuckle, 2008). For example, young cancer patients and survivors may be burdened with re-navigating family roles, such as being perceived as children by parents despite their young adult status because of moving back home for assistance during treatments (Lewis, Jordens, Mooney-Somers, Smith & Kerridge, 2013). As a result, young adults are faced with the tasks of re-navigating and negotiating their independence from their parents and gaining control over their life and life discussions (Millar et al., 2010). The ability to navigate these challenges will be influenced by the individual's ability to cope.

### **Coping with Cancer**

Coping is the cognitive change that takes place via thoughts and behaviors in an individual who is managing internal and external stressors (Lazarus & Folkman, 1984). Coping is the reaction or response to stress expressed behaviorally, emotionally, or cognitively (Skinner & Zimmer-Gembeck, 2007). The perception of the stressor as either positive or negative will contribute to the reaction from the individual (Hildenbrand, Clawson, Alderfer & Marsac, 2011). Coping is a complex phenomenon that depends on a variety of factors such as the individual's age, gender, temperament, culture and spiritual beliefs (Hildenbrand et al., 2011; Hildenbrand, Alderfer, Deatrick & Marsac, 2014). Life experiences before the cancer diagnosis, social support networks, and knowledge about cancer also influence the coping mechanisms (Miedema, Hamilton & Easley 2007).

Coping strategies are described as either emotion-focused or problem-focused (Lazarus & Folkman, 1984). Emotion-focused coping is a strategy where individuals try to alter their thoughts or feelings by reframing the situation positively, discussing feelings with others, or forming supportive relationships (Lazarus & Folkman, 1984). In particular, childhood experiences have been found to contribute to the use of emotion-focused coping strategies (Miedema et al., 2007). Problem-focused coping occurs when the individual tries to change the physical environmental stressors, seeking out knowledge of the problem at hand, or researching for different solutions to the stressor being experienced (Lazarus & Folkman, 1984).

Survivors have been found to use a variety of coping strategies including adaptive and maladaptive strategies (Zucca, Boyes, Lecathelinaias & Girgis, 2010). Research has indicated that for many cancer patients, the initial diagnosis was the most difficult time to cope because of the lack of knowledge relating to treatment and who would be taking care of them during treatment (Kyngäs et al., 2001). After the initial diagnosis, survivors have used problem-focused strategy of seeking out knowledge about their cancer (Miedema et al., 2007). Researchers have found that cancer survivors primarily use distraction coping, such as volunteering, hobbies or activities to cope with cancer (Zaza, Sellick & Hillier, 2005). Avoidant coping strategies (distraction) are maladaptive if the strategy is utilized to take attention away from a problem that needs to be confronted (Folkman & Lazarus, 1988). However, the adaptive or maladaptive nature of the strategy will depend upon the individual's situation and the intent behind the implementation of the coping technique (Folkman & Moskowitz, 2004).

**Adaptation.** Adaptive coping strategies are responses that are actively dealing with the stressor by oneself or with the help of others (Frydenberg, 2014). In addition, adaptive coping is also engaging in strategies that attempt to change the situation for the better (Bellizzi & Blank,

2006). Research has described variables such as cognitive restructuring, social support, and positive emotion regulations to define strategies as positive (bonadaptive) coping (Frank, Blount & Brown, 1997).

**Maladaptation.** In previous research, negative (maladaptive) coping have been defined with avoidance, denial, blaming others, and negative emotional regulations (Frank et al., 1997). Escape-avoidance coping typically is a maladaptive way to cope in situations where the individual cannot control the situation (i.e. waiting for results) (Folkman & Moskowitz, 2004). Helplessness, escape, seeking isolation, opposition, and aggressive responses and behaviors have been found to be associated with maladaptive strategies (Zimmer-Gembeck & Skinner, 2011).

**Social support and coping.** Zucca, Boyes, Lecathelinais, and Grgis (2010) found that social support networks influence coping mechanisms. Recent research indicated that family members, friends, and other survivors served as a support source and inspiration during difficult times (Zebrack et al., 2014). Social networks are important factors contributing to the positive or negative coping. Also, individuals with large supportive strong social networks prior to cancer found these networks to be a helpful resource to their coping (Miedema et al., 2007). Individuals who lack social support or had strained relationships found these relationships to have a negative impact on their coping abilities (Miedema et al., 2007).

Kyngäs et al. (2001) reported that young adults, who used emotion-focused coping during the initial diagnosis of cancer, were able to communicate their difficult feelings about the experience with family members or cancer survivors. Individuals relied on their pre-existing social networks during cancer treatments for support due to lack strength and energy to form new connections (Miedema, et al., 2007). Previous studies reported that survivors who receive high

social support from friends were more likely to view cancer as a challenge and are more involved in their treatments (Cicero, Lo Coco, Gullo & Lo Verso, 2009; Zucca et al., 2010).

Researchers have reported that individuals who lacked social support networks, were more likely to use problem-focused coping because they had to be self-reliant in their coping strategies (Kyngäs et al., 2001). Some cancer patients preferred to adjust to the cancer experience alone (Zebrack et al., 2014), viewing social support more as a stressor than a helpful tool to them (Kent et al., 2012). Additionally, survivors with low levels of social support have been found to utilize maladaptive coping strategies of helplessness/hopelessness (feeling like giving up on the situation) and anxious preoccupation (Zucca et al., 2010). Survivors have reported relationship changes from their support networks after treatment with friends and family being unwilling to discuss feelings related to the survivor having cancer (Zebrack et al., 2014).

### **Perceptions of Familial Resources**

The individual child's characteristics, characteristics of care experienced by the child, and how the child and parent interact over time are factors that contribute to the formation of the parent-child bond (Bowlby, 1969; Parker, Tupling, & Brown, 1979). The care aspects of the parent-child relationship can be positive (affectionate, emotionally supportive, encouraging) or negative (ignoring, neglectful, rejecting) (Schaefer, 1965). Maternal care or nurture can be seen in keeping a close proximal distance to the child and providing for the child's needs (Bowlby, 1969). Control aspects of the parent-child interaction relationship are seen as psychologically manipulative and are negative to the development of the child compared to parental interactions that enable the child to develop independently (Schaefer, 1965). High parental control can be perceived as parenting that is highly supervising, parents who have difficulty separating from the

child, babying children and not encouraging independence (Thomasgard & Metz, 1993). High parental control inhibits the child from developing social competence and autonomy (Thomasgard & Metz, 1993). Thus, the aspects of parental care and control contribute to the formation of the parent-child bond and perception of this bond from a young age and well into adulthood (Bowlby, 1969; Schaefer, 1965).

### **Familial Resources and Influence on Coping**

Kent and colleagues (2012) found that survivors who viewed parents as controlling to be caring and supportive but also made survivors feel that they feel a lack of independence and privacy. Recent research also described that parental overprotection can occur during treatments and can be a source of conflict for the young adult and parent relationship (Epelman, 2013). Young adults have reported experiencing parental overprotection during their transition from cancer treatments to life after cancer (Millar et al., 2010).

As reported by Miedema, Hamilton, Fortin, Easley, and Matthews (2007), if the cancer patient lacked family support or strained family relationships prior to the cancer diagnosis, often times the patient had difficulties coping during treatments. It was reported that lacking family support can result in feelings of loneliness and emotional distress for patients (Howard et al., 2014; Kumar & Schapira, 2013). However, Bellizzi et al. (2012) found cancer to have a positive influence on the relationships between young adults and their mothers. Mothers and young adult survivors have been found to report higher quality relationships compared to survivors' relationships with their fathers (Orbuch et al., 2005). At the same time, research demonstrated that relations between father and young adult, regardless of the relationship quality, were associated with the better psychological, social, and physical outcomes after treatments (Orbuch

et al., 2005). In addition to re-defining parent-adolescent relationships, survivors' spirituality may be strengthened or weakened by the cancer diagnosis (Puchlaski, 2012; Reynolds, Mrug & Guion, 2013).

### **Perception of Spirituality as a Resource and the Influence on Coping**

Spirituality is a multifaceted construct that includes a sense of completeness of oneself, interconnectedness to a higher being, seeking out meaning and purpose in life, and being in harmony with the universe (Cavendish et al., 2004; Schendier & Mannell, 2006; Speraw, 2006). The definition of spirituality may encompass various constructs depending on the individual and thus understanding the individual's meaning assigned to spirituality is important (Schendier & Mannell, 2006). Spirituality was reported to be one of the contributing factors to positive coping with chronic condition/illness (Lima et al., 2013; Schendier & Mannell, 2006; Sira et al., 2014; Speraw, 2006). Spiritual coping is related to the emotional and behavioral adaptations in chronic illness, but the long-term association between these constructs is not fully understood at this time (Reynolds et al., 2013). Spirituality has been found to be a source of comfort and hope for patients and families (Schendier & Mannell, 2006; Sira et al., 2014).

Spirituality has also been helpful to individuals in accepting their cancer diagnosis (Lima et al., 2013). In research with cancer patients, spirituality has generally involved seeking meaning and purpose and accompanies an improved quality of life for patients and families (Lima et al., 2013; Sira et al., 2014). Within the context of cancer research, spirituality is exemplified in the individual's attitudes, thoughts, and emotions (Lima et al., 2013). Positive spiritual coping mechanisms can include: seeking comfort and strength from believing in a Higher Being (Reynolds et al., 2013). Positive spiritual coping is thought to be a protective

factor for pediatric patients from suffering depression later on (Pargament, Smith, Koenig, & Perez, 1998; Park, 2007; Reynolds et al., 2013).

In contrast, negative spiritual coping is an individual having doubts or feelings of abandonment by a Higher Being (Reynolds et al., 2013). While negative spiritual coping, such as feeling abandoned by a higher power, has also been found to lead individuals to try to reconnect with their spiritual beliefs and over time lead to an increase in positive spiritual coping (Reynolds et al., 2013). Negative spiritual coping has been reported to be associated with poorer psychological adjustment (Thuné-Boyle, Stygall, Keshtgar, Davidson & Newman, 2013).

### **Purpose of the Study**

The purpose of the study is to explore coping styles of young adult cancer survivors and to investigate how the perception of parental care and control and spirituality contributes to coping. The Double ABCX model guides this study, by viewing parental care and spirituality as resources to help with coping. Parental control is viewed as a factor contributing to the perception of cancer as a manageable or unmanageable stressor. While the interplay or outcome of these internal resources and perceptions can result in either adaptive or maladaptive coping strategy for young adult cancer survivors thus, current study investigates the following research questions:

1. What coping strategies do young adult cancer survivors predominantly use?
2. Is there an association between coping strategies and perceived maternal care and maternal control?
3. Is there an association between coping strategies and perceived paternal care and paternal control?

4. Is there an association between coping and spirituality?
5. What set of variables (associated with coping) will predict adaptive coping in emerging adults and young adult cancer survivors?

## **Summary**

Previous research reports that emerging adult and young adult cancer survivors are confronted with multiple stressors in addition to the cancer diagnosis. Family and peer relations have been reported to positively or negatively impact how the individual is able to cope with cancer and cancer survivorship. Furthermore, spirituality has been reported as a positive factor in coping with chronic illness. Thus, the current study is further investigates the relationships between age, coping, parental care and control, and spirituality as essential factors in coping.

## **CHAPTER 4: METHODOLOGY**

Current study met ECU's requirements for expedited survey study protocol and was approved by the Institute Review Board at East Carolina University (ECU) on April 1, 2015 (See Appendix A). In order to better understand emerging adult and young adult coping, and evaluate the contribution of perceived maternal/paternal care and control and spirituality to overall coping with cancer in this population, an online survey that included appropriate measures in addition to demographic information was created (See Appendix C).

### **Participants**

The study's population was young adults cancer survivors between the ages of 18-40. Cancer survivors were defined as any individual diagnosed with cancer, including individuals recently diagnosed, individuals currently in treatment, and individuals in remission (Decker et al., 2007; DeSantis et al., 2014). The inclusion criterion for the study was (a) being a young adult cancer survivor between the ages of 18- 40, (b) diagnosed as having cancer before the age of 40 and (c) treated for cancer. The age range was selected based on the developmental theories of emerging adulthood and young adulthood (Arnett, 2007). Exclusion criteria was being an individual younger than 18 and older than 40 years old.

### **Procedure**

A Qualtrics survey was advertised to young adult cancer survivors through online young adult cancer forums, young adult cancer Facebook groups, and through tweets on Twitter. The survey was posted in different Facebook groups with a reminder posted a month after the initial posting in a Facebook group by the principle investigator. No reminder was posted in Facebook

groups where a moderator posted the advertisement. The link to the study's survey was open from April 30, 2015 to October 5, 2015.

After participants read the advertisement script, they were asked to click on a link to the Qualtrics survey. The informed consent process consisted of participants reading the study description and consenting to participate by clicking "*I agree to participate*" (See Appendix B). Participants answered a series of demographic questions including medical information, the Brief COPE scale (Carver, 1997), the Spiritual Insight and Behavioral Scale (Sira & McConnell, 2008), the Parental Bonding Instrument (Parker et al., 1979), and a series of open-ended questions on coping.

## **Instruments**

**Demographic information.** Participants were asked to demographic information and information about their cancer diagnosis. Participants reported on their gender, age, race, marital status, educational obtainment, religious beliefs, and childhood family structures. Participants also reported on the age of their cancer diagnosis, how long it had been since treatment, whether they had a relapse or a secondary cancer, and indicated their primary caregiver during treatment.

**Brief COPE.** Coping was measured by Brief COPE (Carver, 1997) scale, which assesses different coping styles in cancer population. The Brief COPE is a shorter version (28 items) of the COPE Inventory (Carver, 1997). The scale is a 4-point Likert type scale that assesses the following coping mechanisms: *self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame* (Carver, 1997). The scale includes items such as "*I've been getting emotional support from others*", "*I've been trying to*

*see it in a different light, to make it seem more positive*”, and “*I’ve been giving up the attempt to cope*” (Carver, 1997). The Brief COPE scale does not group coping mechanisms into problem-focused or emotion-focused coping styles but rather describes the strategies for a population (Carver, 1997). The Brief COPE scale used loaded factorial analysis of the COPE Inventory to eliminate questions and focus on relevant items and scales to breast cancer patients (Carver, 1997).

For this study, an adaptive and maladaptive coping scale was created from the items of the Brief COPE scale based on coping literature (Frank et al., 1997; Freydenberg, 2014). The Brief COPE scale has previously been separated into adaptive and maladaptive coping scales (consistent with the theory that grounds this study) and found to be reliable (Berenbaum & Baker, 2007; Walker, Zona & Fisher, 2006). The adaptive coping scale was calculated as the sum of *active coping, positive reframing, humor, acceptance, venting, use of emotional support, use of instrumental support, planning* and *religion* items. The reliability coefficient for adaptive coping scale for the current sample was  $\alpha = .84$ . The maladaptive coping subscale was calculated by the sum of *behavioral disengagement, denial, distraction, substance use, and self-blame* items. The reliability coefficient for the maladaptive coping scale for the current sample was  $\alpha = .76$ . High scores indicated high levels of utilization of adaptive/maladaptive coping strategy.

**Parental Bonding Instrument.** Perception of Maternal and Paternal Care and Control were measured with the Parental Bonding Instrument (PBI) (Parker et al., 1979). The PBI is a self-report retrospective questionnaire with a 4-point Likert-scale that consists of 25 identical items for the individual’s perception of his/her mother and perception of his/her father (e.g., “*Mother/father was affectionate to me,*” “*Mother/father tried to control everything I did*”). The PBI yielded two scale scores for each parent: Mother/Father Care and Mother/Father Control,

which were scored and computed by the standard instructions. High scores indicated high levels of care and high level of control, as perceived by the participant. High care cut off scores for mothers was a score of 27 and for fathers was a score of 24 (Parker et al., 1979). Low control cut off scores for mothers was a control score of 13.5 and for fathers a score of 12.5 (Parker et al., 1979). Alpha coefficients for maternal care and maternal control scale are  $\alpha = .96$  and  $\alpha = .87$ , correspondingly. Reliability alpha coefficients for paternal care and paternal control scale for the current sample are  $\alpha = .94$  and  $\alpha = .86$ , respectively. The PBI has been found to be a reliable measure over time, with little influence of individual characteristics (gender, life experiences, current mood) overtime on perceived maternal/paternal care and control (Wilhelm, Niven, Parker, & Hadzi-Pavlovic, 2005).

**Spiritual Insight and Behavioral Scale.** Spiritual beliefs in life and coping in the healthcare setting were assessed by the Spiritual Insight and Behavioral Scale (Sira & McConnell, 2008). Eight items from the scale were selected to-assess participants' feelings on spirituality, spirituality's role in their life, their feelings and perceptions on spirituality within their care and coping, and the role of their spirituality in their culture. Participants were asked to rate their perception on a Likert type scale from 0-2. High score ratings indicated a higher emphasis on spirituality. This scale included statements such as "*I view spirituality as an important part of my healing process*", "*Prayer tends to get my mind of problems*", and "*My own personal beliefs and spirituality are my main sources from which I receive hope, strength, comfort, and peace*". The reliability coefficient of the Spiritual Insight and Behavioral Scale for the current sample was  $\alpha = .82$ .

**Open ended questions.** Participants responded to open-ended questions that asked what other helpful coping mechanisms were used during cancer treatments and after cancer treatments. They were asked if the following factors (cancer type, age, and gender) were important when getting support from other cancer survivors and if their family (mother and father) were supportive since their cancer diagnosis. Participants were also asked what else should be known about having cancer as a young adult.

## Data Analysis

Data was downloaded from Qualtrics into a SPSS file that has been coded by the Qualtric survey. IBM SPSS Statistics 20 was used to analyze data. Descriptive statistics were used to describe the demographic characteristics of the sample, Standard Deviations, and Means for each scale. Independent *t*-tests were performed to compare Brief COPE subscale means between emerging adults and young adults and to compare groups of survivors with a year or less out of treatment to survivors two or more years out of treatment. Pearson Correlations between study variables were performed between measured variables to evaluate the associations. For all analyses  $\alpha < 0.05$  was used as statistically significant difference between groups. A partial correlation was performed between variables controlling for age and time since treatment. A two-step linear regression analysis was used in order to analyze key variables contribution to coping. In step one of the linear regression were the individual characteristics of age and time since treatment and in step two were the psychological variables of perceived maternal/paternal care and control and spirituality. Open-ended question responses were analyzed by the principle investigator and organized into themes for reporting.

## **Summary**

The current study assesses the overall coping strategies of emerging adult and young adult cancer survivors. Thus, the data analysis described was used to evaluate coping strategies in study population, investigate the internal resources that contribute to adaptive and maladaptive coping in this population. Insight from this study could provide researchers with a better understanding of the coping process.

## **CHAPTER 5: RESULTS**

The current study was exploratory in nature to describe coping strategies, perceived parental care and control, and spirituality of emerging adults and young adult cancer survivors. This section will answer the following research questions.

1. What coping strategies are used predominantly by young adult cancer survivors?
2. Is there an association between coping strategies and perceived maternal care and maternal control?
3. Is there an association between coping strategies and perceived paternal care and paternal control?
4. Is there an association between coping and spirituality?
5. What set of variables (associated with coping) will predict adaptive coping in emerging adults and young adult cancer survivors?

### **Participants Demographics**

A sample of 210 participant cancer survivors were recruited from online forums, Facebook groups, and Twitter. The sample consisted of 181 (86.2%) females and 29 (13.8%) males. While the study focused on two different age groups of young adult survivors, emerging adults ages 18-30 and young adults ages 31-40, current sample included 117 (55.7%) emerging adult participants with mean age of 25.88 ( $SD=3.18$ ) and 93 (44.3%) young adult participants with mean age of 34.39 ( $SD=2.62$ ).

Participants of the study were primarily Caucasian 85.7% ( $n=180$ ) with 5.2% ( $n=11$ ) identifying as Hispanic or Latinos, 5.7% ( $n=11$ ) identifying as Multi-Racial, 1.9% ( $n=4$ ) as Asian Americans, 1.0% ( $n=2$ ) as African Americans and .05% ( $n=1$ ) as American Indian or Native

Alaskan. The majority of participants reported themselves as Christians 57.1% ( $n=124$ ). All reported demographic information of study participants including, marital status, educational attainment, and religious affiliation are presented in Table 1.

### **Participant Cancer Information**

In addition to demographic information, participants also reported on information related to their cancer diagnosis. There were 120 (57.1%) participants diagnosed with cancer during emerging adulthood, 53 (25.2%) diagnosed during young adulthood, 15 (7.1%) participants were diagnosed during adolescence, 12 (5.7%) participants diagnosed during childhood, four (1.9%) participants had diagnoses during childhood and adulthood, and six (2.9%) participants did not report the age of their cancer diagnosis.

The sample included 41(19.5%) participants who had a relapse and 21 (10%) participants who reported to have secondary cancer. Among study participants, 88 (41.9%) reported to currently be in treatment or have been out of treatment for less than one year. While 34.8% ( $n=73$ ) participants reported that their mother was primary caregiver during treatment, 41% ( $n=86$ ) indicated that a significant other or spouse was their primary caregiver during treatment. More details on the participant's cancer demographic information are presented on Table 2.

Table 1

*Demographic Characteristics of Study Participants (N=210)*

Characteristic	Category	Number	Percentage
Gender	Female	181	86.2%
	Male	29	13.8%
Race	Caucasian	180	85.7%
	African American	2	1.0%
	Hispanic or Latino	11	5.2%
	Asian American	4	1.9%
	American Indian or Alaska Native	1	0.5%
	Multi-Racial	12	5.7%
Age	18-30	117	55.7%
	31-40	93	44.3%
Marital Status	Single	125	59.5%
	Married	75	35.7%
	Divorced	10	4.8%
Education	High School Diploma	9	4.2%
	Some College	46	21.9%
	Associates Degree	11	5.2%
	Bachelors Degree	82	39.0%
	Masters Degree	51	24.3%
	Professional Degree	5	2.4%
	Doctoral Degree	6	2.9%
Religious Beliefs	Christian	124	57.1%
	Jewish	8	3.8%
	Muslim	2	1.0%
	Buddhist	4	1.9%
	Unitarian/Universalist	5	2.4%
	Native American	1	0.5%
	Spiritualist	13	6.3%
	Agnostic	10	4.8%
	Atheist	11	5.3%
	Not Religious	17	8.2%

Table 2

*Participant's Cancer Information (N=210)*

Characteristic	Category	Number	Percentage
Age of Cancer Diagnosis	Childhood	12	5.7%
	Adolescence	15	7.1%
	Emerging Adulthood (18 -30)	120	57.1%
	Young Adulthood (31-40)	53	25.2%
	Childhood and Adulthood	4	1.9%
	No Response	6	2.9%
Time since treatment	Currently undergoing treatment	41	19.5%
	Less than a year	47	22.4%
	1 year	27	12.9%
	2 years	26	12.4%
	3 years	16	7.6%
	4 years	10	4.8%
	5 years	10	4.8%
	6 years or more	32	15.3%
	No Response	1	0.5%
Have had a relapse	Yes	41	19.5%
	No	169	80.5%
Have had a secondary cancer	Yes	21	10.0%
	No	189	90.0%
Primary Caregiver	Mother	73	34.8%
	Father	12	5.7%
	Both Parents	5	2.4%
	Sibling	3	1.4%
	Significant Other or Spouse	86	41.0%
	Friend	7	3.3%
	Self	17	8.1%
	Caregiver varied throughout	5	2.5%
	Homestay Parents	1	0.5%
	Godmother	1	0.5%

## Coping Strategies

Participants coping with cancer was measured by Brief COPE scale (Carver, 1997) a measure that consists of 14 subscales. Study participants reported using several different coping strategies. Brief COPE subscales were broken into Adaptive Coping and Maladaptive Coping. Adaptive coping was calculated by the sum of the *Active, Emotional Support, Instrumental Support, Venting, Positive Reframing, Planning, Humor, Acceptance, and Religion* subscale scores. Maladaptive Coping was the sum of the Brief COPE subscales of *Behavioral Disengagement, Denial, Substance Use, Self-blame, and Distraction* scores. The decision to separate the specific categories of adaptive and maladaptive coping originated from literature on coping strategies and further backed by the theory that grounds this study. The mean and ranges for Adaptive and Maladaptive coping scales are reported on Table 3.

Table 3

*Scale Means, Standard Deviations, Ranges, and Cronbach Alphas*

Scale	Mean	Standard Deviation	Range	Cronbach Alpha
Adaptive Coping	47.88	9.11	26-67	.84
Maladaptive Coping	19.54	5.15	11-35	.76
Maternal Care	24.52	10.40	0-36	.96
Maternal Control	14.76	8.17	0-39	.87
Paternal Care	23.06	9.66	0-36	.94
Paternal Control	11.80	7.58	0-39	.86
Spiritual Behavioral Insight	8.63	3.71	1-14	.82

**Brief COPE subscales.** The means and standard deviations were calculated for all the Brief Cope subscales are reported on Table 3. The cut off score for high adaptive was 48.88, the cut off score for low adaptive was 46.88. There were 96(48%) participants with a high adaptive coping score ( $M=55.69$ ,  $SD=4.64$ ), 84 (42%) participants scored low on adaptive coping ( $M=39.02$ ,  $SD=4.94$ ). Twenty (10%) participants did not score in the high or low adaptive categories. The cut off scores for high maladaptive coping and low maladaptive coping were 20.54 and 18.54 respectively. Current sample also included 70 (35%) participants with high maladaptive coping scores ( $M=25.27$ ,  $SD= 3.74$ ) and 98 (49%) participants had low maladaptive coping scores. Thirty-two (16%) participants did not fall into the high or low maladaptive groups.

An independent sample  $t$ -test was conducted to compare Brief COPE subscales means in the emerging adult and young adult populations. There were no significant differences in the means between emerging adults and young adults on any Brief COPE subscale. An independent sample  $t$ -test was conducted to compare Brief COPE subscales means between survivors one year or less out of treatment to survivors two or more years out of treatment. There was a significant difference between Adaptive coping scores between survivors one year or less out of treatment and survivors two or more years out of treatment with  $t$  (194) = 2.19,  $p=.029$ . In addition, a significant difference in the *emotional support* scores between survivors one year or less out of treatment and survivors two or more years out of treatment with  $t$  (202)=2.14,  $p=.034$ . Another significant difference in the *venting* scores in the scores between groups of survivors one year or less out of treatment and survivors two or more years out of treatment with  $t$  (203)=2.76,  $p=.006$ . There was a significant difference in *humor* scores between groups of survivors one year or less out of treatment and survivors two or more years out of treatment with

$t(202)=2.30, p=.023$ . There were no other significant differences in Brief COPE subscores means between survivors one year or less out of treatment and survivors two or more years out of treatment.

Table 4

*Means and Standard Deviations of Coping Subscales*

Variables	Overall (N=206)	Emerging Adults (n=113)		Young Adults (n=93)		One year or less out of treatments (n=115)		Two or more years out of treatment (n=90)		
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Active Coping	5.96	1.49	5.78	1.48	6.17	1.49	6.07	1.49	5.79	1.49
Emotional Support	5.54	1.83	5.43	1.89	5.67	1.75	5.80	1.83	5.26	1.77
Instrumental Support	4.95	1.66	4.81	1.62	5.12	1.71	5.09	1.69	4.81	1.60
Positive Reframing	5.53	1.91	5.54	2.01	5.53	1.79	5.54	2.03	5.11	1.75
Religion	4.04	2.13	3.96	2.18	4.14	2.07	4.04	2.14	4.02	2.14
Acceptance	6.32	1.43	6.39	1.39	6.25	1.47	6.40	1.44	6.24	1.41
Planning	5.51	1.76	5.42	1.69	5.62	1.79	5.68	1.73	5.27	1.77
Humor	5.33	1.96	5.29	6.39	5.38	1.98	5.61	1.92	4.98	1.98
Venting	4.71	1.50	4.66	1.62	4.77	1.35	4.97	1.47	4.40	1.49
Distraction	5.93	1.43	6.00	1.46	5.84	1.39	5.96	1.43	5.89	1.44
Self-Blame	4.34	1.97	4.33	1.92	4.34	2.02	4.28	1.95	4.37	1.97
Substance Use	3.04	1.58	3.12	1.69	2.93	1.44	3.01	1.64	3.07	1.52
Behavioral Disengagement	3.00	1.33	3.04	1.43	2.95	1.21	3.08	1.36	2.89	1.29
Denial	3.21	1.52	3.27	1.62	3.13	1.38	3.28	1.58	3.09	1.41

**Adaptive behavior.** Among study participants 85 (26.8%) of them reported “Acceptance” as a highly used coping behavior. The second most reported coping behavior was “Humor” with 43 (20.9%) participants highly reported this coping behavior. “Active coping” and “Positive reframing” were equally reported among participants as the most common coping behavior with 41 (20%) participants reporting using these behaviors.

**Maladaptive behavior.** Among maladaptive behavior items “Distraction” behavior was highly recognized by 33(16.2%) participants as coping strategy they relied on. The second most reported maladaptive coping strategy was “Self-blame” with 23 (11.2%) participants reported on using this behavior in their coping strategy.

### **Parental Perception**

The Parental Bonding instrument (Parker et al., 1979) was used to evaluate participant’s perception of Maternal Care and Maternal Control. Scores for *Maternal* and *Paternal Care and Control* were calculated based on scale instructions (Parker et al., 1979). There were scale items that were reversed scored per scale instructions (Parker et al., 1979). All items were answered on four point Likert-type scale where high numbers are indicative of high mutual trust and care for *Care* scale as perceived by participants; and high level of control by each parents as perceived by participants for *Control* scale.

**Maternal care and maternal control.** High care cut off scores for mothers was a score of 27 (Parker et al., 1979). Low control cut off scores for mothers was a control score of 13.5 (Parker et al., 1979). In the sample, there were 104 (56.22%) participants who reported high Maternal Care ( $M=32.14$ ,  $SD=2.86$ ) and 81(43.78%) participants who reported low Maternal Care ( $M=14.74$ ,  $SD=8.11$ ). While there were 93(50.27%) participants who perceived high

Maternal Control ( $M=21.42$ ,  $SD=5.73$ ), 92 (49.73%) participants reported low Maternal Control ( $M=8.03$ ,  $SD=3.25$ ). Means, standard deviations and reliability coefficients alphas for the scales are presented on Table 3.

**Paternal care and paternal control.** High care cut off scores was a score of 24 (Parker et al., 1979). Low control cut off for fathers was a score of 12.5 (Parker et al., 1979). Among study participants 91 (56.52%) participant scored high on Paternal Care ( $M=30.26$ ,  $SD=3.58$ ) and 70 (43.49%) participants scored low Paternal Care ( $M=13.7$ ,  $SD=6.52$ ). In this sample, 65 (43.37%) participants reported high Paternal Control ( $M= 19.43$ ,  $SD=5.16$ ) and 96 (59.63%) participants who perceived low Paternal Control ( $M=6.63$ ,  $SD=3.47$ ). Means, standard deviations, and alphas for scales are reported on Table 4.

## **Spirituality**

Spirituality was measured by the Spiritual Behavioral Insight Scale (Sira & McConnell, 2007) where participants rated the role of spirituality in their coping on a three point Likert type scale. A high score is indicative of high importance/emphasis on spirituality in individual's life. While the majority of participants identified themselves as Christians 124 (57.1%), remaining 42.9% of participants identified as Spiritualist, Agnostic, Atheist, Jewish, Muslim, Buddhist, Universalist, Native American or not religious please refer to Table 2 for specific information.

The cut off scores for high spirituality was 9.6 and the cut off score for low spirituality was 7.6. The current sample had 83 (41.5%) participants scored high on spirituality scale ( $M=12.37$ ,  $SD=1.50$ ) and 82 (41%) participants scored low on spirituality scale ( $M=4.89$ ,  $SD=1.71$ ), indicating low importance of spirituality in their life and coping. Thirty-five (17.5%)

of participants were in the in-between group between high spirituality and low spirituality indicating a moderate importance of spirituality in their life and coping.

Table 5

*Correlations between Key Variables for entire sample (N = 210)*

Variables	1	2	3	4	5	6	7	8
1. Adaptive coping	-							
2. Maladaptive coping	-.074	-						
3. Maternal Care	.149*	-.213**	-					
4. Maternal Control	-.032	.213**	-.460**	-				
5. Paternal Care	.144	-.167*	.229**	-.296**	-			
6. Paternal Control	-.047	.083	-.242**	.429**	-.338**	-		
7. Spirituality	.360**	-.047	.052	.086	-.041	.016	-	
8. Age	.158*	-.029	-.151*	.058	-.049	.075	.110	-
9. Time out of treatment	-.244**	.012	.095	-.110	.081	-.087	.021	-.110

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

### Correlation Analyses

A Pearson-Product correlation was performed on study variables to determine the relationship between Adaptive Coping, Maladaptive Coping, Parental Care, Parental Control,

and Spirituality. In addition to the psychological variables, participants' demographic variables of Age and Time since treatment were included in the correlational analyses. Correlation analyses were performed across these variables revealing some significant relationships. While there was a negative correlation found between Time out of treatment and Adaptive coping ( $r=-.244, p<.001$ ), a moderately positive correlation was found between Age and Adaptive coping ( $r=.158, p<.025$ ). These correlations indicate that Time since treatment and Age in this group of young adults are associated with Adaptive coping.

**The relationship between coping and parental care/control.** A Pearson-Product Correlation was performed between the Adaptive Coping scale Maternal Care scores, Maternal Control scores, Paternal Care scores, and Paternal Control scores. A moderately positive significant correlation was found between Adaptive Coping scores and Maternal Care ( $r=.149, p<.049$ ), indicating that Maternal Care is associated with Adaptive Coping. A partial correlation was computed between Maternal Care and Adaptive Coping controlling for age and time since treatment. A partial correlation between Maternal Care and Adaptive Coping was found ( $r=.167, p<.044$ ). No significant correlations were found between adaptive coping and Maternal Control scores, Paternal Care scores, and Paternal Control scores (See Table 5).

Correlational analyses were also performed on Maladaptive Coping scores and Maternal Care scores, Maternal Control scores, Paternal Care scores, and Paternal Control scores. A positive significant correlation was found between Maternal Control and Maladaptive coping scores ( $r=.213, p<.004$ ). A partial correlation was then computed between Maternal Control and Maladaptive coping controlling for age and time since treatment. There was a significant partial correlation found between Maternal Control and Maladaptive coping ( $r=.221, p<.007$ ). A significant negative correlation was found between Maladaptive coping and Maternal Care ( $r=-$

.213,  $p < .004$ ). There was a moderately negative correlation between Maladaptive coping and Paternal Care ( $r = -.167$ ,  $p < .049$ ). These results indicate that Paternal Care and Maternal Care/Control are associated with Maladaptive Coping. A significant partial correlation was found between Maternal Care and Maladaptive coping ( $r = -.176$ ,  $p < .034$ ) and between Paternal Care and Maladaptive coping ( $r = -.179$ ,  $p < .031$ ). No significant correlation was found between Maladaptive coping and Paternal Control (See Table 5).

**The relationship between coping and spirituality.** A Pearson-Product Movement Correlation was performed between the two coping scales (Adaptive and Maladaptive) and Spirituality. A positive significant correlation was found between Adaptive coping and Spirituality ( $r = .360$ ,  $p < .000$ ), indicating that spirituality contributes to Adaptive coping. A partial correlation was then computed between Adaptive coping and Spirituality controlling for Age and Time since treatment. A significant partial correlation was found between Adaptive coping and Spirituality ( $r = .348$ ,  $p < .000$ ). No significant correlation was found between maladaptive coping and Spirituality (See Table 5).

## **Regression Analysis**

Multiple regression equation was used to estimate the relative contribution of the independent variables to the prediction of adaptive and maladaptive coping among study participants. Prior to the regression analysis, the Age variable was transformed to include text variable responses. The age variable was run as a continuous variable. Time since treatment variable was run as a categorical variable with eight different categories. The categories were *currently in treatment, less than a year out of treatment, one year out, two years out, three years out, four years out, five years out, and six or more years out.*

**Adaptive coping.** Due to the exploratory nature of the study, two blocks in step forward regression analysis was used. The first block consisted of the demographic (individual) variables and included *Age* and *Time since treatment*. The second block consisted of psychological variables that included *Maternal Care*, *Maternal Control*, *Paternal Care*, *Paternal Control*, and *Spirituality*. The relative contributions of the independent variables are demonstrated in Table 6.

Table 6

*Summary of Regression Analysis for Variables Predicting Adaptive coping (N=150)*

Variable	Step 1			Step 2		
	B	SE B	$\beta$	B	SE B	$\beta$
Age	.289	.129	.179**	.292	.121	.181**
Time since treatment	-.729	.292	-.199**	-.875	.276	-.236***
Maternal Care				.157	.074	.184**
Maternal Control				.046	.100	.043
Paternal Care				.148	.074	.160*
Paternal Control				-.013	.098	-.011
Spirituality				.739	.179	.307****
<i>R Squared</i>			.082			.238
<i>R</i>			.286			.488

Note. \* $p \leq .05$       \*\* $p \leq .01$       \*\*\* $p \leq .001$       \*\*\*\* $p \leq .000$

▲ *R squared change in step 2 accounted for 15.6% of variance in adaptive coping pattern*

Thus, in step one, demographic variables *Age* and *Time since treatment* made a significant contribution and consequently accounted for 8.2% of variability in dependent variable (Adaptive coping). In step two, psychological variables explained an additional 15.6% of the variance in

the adaptive coping among cancer survivors with *Maternal Care*, *Paternal Care*, and *Spirituality* as significant predictors to adaptive coping. In other words, participants who reported to cope with cancer in adaptive ways, tend to be older in age (young adults), more recently received cancer treatments, perceived satisfactory (high) Maternal and Paternal Care, and also reported relying on their spirituality as a source of strength.

**Maladaptive coping.** While there were few significant negative correlations between Maladaptive coping and Maternal ( $r=-.213, p<.004$ ) and Paternal care ( $r=-.167 p<.049$ ), a positive association between Maternal control and Maladaptive coping ( $r=.213, p<.004$ ), regression analysis (controlling for Age and Time since treatment) did not produce any significant associations between study variables in prediction of Maladaptive coping.

### **Open Ended Questions**

Among open-ended remarks, participants had an opportunity to report about their parent support and questions about support groups. The summary results of open-ended questions are presented in Table 7. Participants also had an opportunity to report on three open-ended questions related to coping strategies and other info that may not have been addressed in the survey. Sixty-three (30%) participants responded to the question, *what are other helpful ways to cope during treatments*, 82 (39.04%) participants responded to the question, *what are other helpful ways to cope after treatments*, and 81 (40.5%) participants responded to, *what else should be known about having cancer as a young adult*. Those responses were organized by themes and presented in this section.

**Challenges of young adults facing cancer.** The first common theme that emerged from responses was focused on *the challenge of having cancer and facing the developmental tasks for young adults*. Fifteen (18.5%) participants mentioned that being a young adult by societal

expectations and facing cancer at the same time was a challenge. One participant reported that she was in a state of “*arrested development*” since her diagnosis:” –*like I haven’t gone through the life-markers or stages of a ‘typical’ young adult*”. Another participant described it as “*Giving up your life in the prime of your life (work, raising families, social aspects)*”. Some respondents ( $n=5$ , 6.2%) expressed the challenge of giving up their independence as a young adult when faced with cancer.

Another major theme presented by participants in their remarks was the notion of the chronic nature of the disease and described “*cancer as never ending*”. Eleven (13.6%) participants discussed the concept of dealing with cancer for the remainder of their life, dealing with the long-term effects of cancer treatment or/and the emotional toll of cancer on them. Some survivors ( $n=5$ , 6.2%) expressed that it was more difficult to cope after cancer treatments had ended because they felt unprepared to deal with these new emotional/physical effects. Thirteen (16.1%) participants discussed having cancer as a young adult as a very isolating experience because they were unable to relate to other cancer patients at their treatment centers and lost connections with friends during cancer treatments. As one survivor expressed, “*the hardest part is after treatment is over, your support system largely deteriorates and you feel way more alone.*”

**Importance of support in coping.** About 21.5 % ( $n= 45$ ) of participants reported that they attend support groups for cancer survivors and 50% ( $n=105$ ) of them indicated that having support from a survivor with the same type of cancer was important to them. The majority of survivors reported that their mothers ( $n=151$ , 71.9%) and fathers ( $n=126$ , 60.0%) were supportive since diagnosed with cancer.

Survivors mentioned support from friends, family members, or other cancer survivors. Twenty-three (28.05%) individuals indicated that talking about their cancer experience after cancer was helpful to them, whether it be with a therapist, support groups/survivors, friends or family members. During treatment, 22 (34.92%) participants indicated that their friends were helpful to their coping, during cancer treatments. Participants reportedly “*enjoyed spending time with their friends*” and “*talking with friends about their feelings*” as helpful strategies they used during cancer treatments. The importance of friends in relation to coping continued well after cancer treatments, with 13 (15.9%) respondents reporting that spending time with friends after treatment was a helpful coping strategy.

Nine (14.29%) participants stated that interactions with both friends and family were important to their coping during treatment and 11(13.6%) participants mentioned friends and family in their coping activities after treatment. In particular, five (7.94%) survivors highlighted how important it was to “*communicate with friends and family about their feelings*” during treatment and four (4.9%) participants stated it was also important after treatments. Eight (12.70%) survivors stated that during treatment their families were a source of support, with some respondents highlighting their own children as important factor for their coping. Seven (8.5%) survivors also mentioned the importance of their family after treatment. One participant stated “*My daughter was a huge part of my coping. Being around her and doing little things with her helped me cope a lot.*”

Participants also reported that new connections they made during treatments were helpful to their coping. One hundred and twenty-five (59.5%) participants reported that they preferred to connect with other survivors that were similar in age. Thus, 13 (20.63%) participants mentioned connecting with other young adult survivors during treatments. One of them reported: “*When I*

*finally met other young adult survivors that could understand everything I'd been through and actually talk about the cancer process without getting uncomfortable is when I finally was able to fully cope with everything.*" The connection with other survivors continued well after cancer treatments as well, with 20 (24.7%) survivors expressing the need to connect with other survivors. As one survivor stated "*only other cancer survivors can truly understand feeling and thoughts of another cancer patient/survivor.*"

**Coping activities.** Twenty-nine (32.6%) participants discussed the importance of distractions such as reading books or watching T.V. or movies during cancer treatments. In addition to distraction activities, 11(17.5%) survivors expressed the need to get away from treatment centers, by traveling on day trips or going outside for walks. After treatments, 29 (35.37%) participants reported using exercise, such as running, walking, going to the gym, yoga classes as a useful and helpful coping mechanism. Several respondents ( $n=6$ , 7.3%) reported using exercise and discussed how focusing on nutrition was important to them after cancer treatments.

**The importance of normalcy.** After cancer treatments, nine (10.98%) participants reported moving on toward new life experiences, such as getting a new job and setting future goals as helpful. Planning for the future was almost equally important to individuals during cancer treatments, as one respondent stated during treatments she focused "*on planning her wedding.*" During treatment, 14 (22.2%) participants expressed they attempted to keep their life as normal as possible, whether it be keeping up with "*having a routine*", "*doing my make up*", "*focusing on graduate school*", or "*working from the chemo chair*". There were few participants ( $n=7$ , 8.5%) coping after treatments included returning to life activities, such as "*taking care of my child*", "*returning to work*", and "*returning to physical activities such as running*".

Table 7

*Summary of responses related to family and group support for cancer survivors*

Question	Responses	Number	Percentage
Has your mother been supportive since your cancer diagnosis?	Yes No	151 25	71.9% 11.9%
Has your father been supportive since your cancer diagnosis?	Yes No	126 28	60.0% 13.3%
Do you attend any support groups?	Yes No No, I have in the past No, I would If I could find one in my area	45 73 22 41	21.5% 34.8% 10.5% 19.5%
Having support from a survivor with the same cancer as me is important.	Yes No I just prefer to have support from other cancer survivors, regardless of their cancer diagnosis	105 20 55	50.0% 9.5% 26.2%
Connecting with a survivor as the same gender as me is important.	Yes No	115 66	54.8% 31.4%
I prefer to connect with survivors around my age.	Yes No I haven't been able to connect with survivors around my age but I would like to	125 12 44	59.5% 5.7% 21.0%

**Summary**

The current study provides a description on coping with cancer for emerging and young adult population. Thus, there were few significant associations between study variables to explain how emerging adult and young adult cancer survivors cope. High Maternal Care and high Spirituality were found to be associated with Adaptive coping. Participant's age and time since treatment were found to be factors contributing to Adaptive coping. High importance of

Spirituality in life and coping, high perceived levels of Maternal Care and Paternal Care were found to be predictive factors for Adaptive coping. These results provide insight into the overall coping and factors associated with adaptive coping.

## **CHAPTER 6: DISCUSSION**

Coping is a complex phenomenon with several factors contributing to an individual's ability to cope. With limited research on the emerging adult and young adult cancer survivors, this study's purpose was to explore what coping strategies cancer survivors use and what factors are associated with their abilities to cope. Thus, overall coping strategies of emerging and young adults are described and how study variables such age, time since treatment, the survivor's perception of parental care/control, and spirituality are associated with coping strategies (adaptive or maladaptive) are discussed in this section.

### **Coping Strategies**

Cancer survivor numbers have greatly increased over the years because of the advances in medicine and technology (Ward et al., 2014). These advances have made cancer a chronic illness after patients have endured long and painful treatments like chemotherapy and radiation (Ward et al., 2014; Compas, Jaser, Dunn, & Rodriguez, 2012). However, despite the increase in the number of survivors, there are only a few studies investigating how emerging adult and young adult cancer survivors cope.

Therefore, the current study found that young adult cancer survivors use a variety of adaptive and maladaptive coping behaviors/strategies when dealing with disease. While a majority (48%) of participants ( $n=96$ ) used adaptive (positive) coping strategies, 70 participants (35%) used high maladaptive (negative) coping. The study also found that 20 participants (10%) were moderately using adaptive coping strategies and 32 participants (16%) moderately using maladaptive coping strategies. These findings highlight that individuals in current study use a variety of coping strategies and those coping strategies may be dependent upon situational

factors. Participants may be using different coping strategies to find the best strategy for the situation and for the individual.

Participants who reported adaptive coping frequently reported *acceptance*, *humor*, *active coping*, and *positive reframing* as coping strategies, which are congruent with previously reported findings. Acceptance, active coping, positive reframing, and humor as coping strategies were described and supported by previous research in cancer populations (Kershaw, Northouse, Kritpracha, Schafenacker & Mood, 2007; Lauver, Connolly-Nelson, & Vang, 2007; Shapiro, Dey, McCue, Heyman & Haller, 2010; Zaza et al., 2005).

For the 35% of participants who scored high on maladaptive coping strategies, the most utilized behaviors were *distraction* and *self-blame*. Open-ended remarks from participants supported distraction as a helpful coping strategy during treatment. Those participants reported watching movies and T.V. and reading books while coping with cancer treatments. In previous research, distraction coping was found to be a highly utilized coping strategy among cancer populations (Kershaw et al., 2007; Lauver et al., 2007; Zaza et al., 2005). The open-ended remarks suggest that *distraction* may not be used as a maladaptive coping strategy during treatment because some participants expressed relying on distraction during treatments. Thus, distraction may be a useful tool during treatment when participants are actively engaged in painful and stressful medical situations. However, Folkman and Lazaurus (1988) indicated distraction to be maladaptive strategy if it used to take attention away from problems that need to be addressed. Self-blame also has previously been found in research to be associated with higher levels of depression in cancer populations (Shapiro et al., 2010). The findings of the current study indicate that there is a portion of young adult cancer survivors struggling with

coping/adapting to cancer and use self-blame, distractions, or alcohol as coping tools for some but not useful or supportive tool in adaptive coping.

**Coping and individual characteristics (age and time since treatment).** Current results indicated that individual characteristics (age and time since treatment) were found to contribute to more adaptive coping strategies within the emerging adult and young adult populations. While study participants ranged in age (18-40), the current study has found the individual's age to be a factor contributing to the ability to adaptively cope. Thus, findings of the current study indicate that those adaptive coping strategies to be more likely present in older young adults who more likely have the internal and external resources available to them. The internal resources maybe linked to age and maturity (i.e., a defined sense of self, competence, and identity) (Arnett, 2007). Emerging adults (18-25) are still developing identities (personal and professional), forming relationships (romantic and friendships), discovering their own personal set of beliefs and values, and only recently have become independent from their families (Arnett, 2007).

This developmental and transitional time in emerging adulthood is defined in literature by self-discovery (Arnett, 2007). At the same time, emerging adults have limited practical knowledge or experiences with dealing with life stressors on their own compared to older young adults. According to the ABCX Model, available resources and previous experiences managing stressors are contributing factors to the individual's adaptation to stressors (McCubbin & Patterson, 1983); thus, young adults with more life experiences in life stressful situations had more time to develop and refine internal/external resources/strategies in coping with life crises and are better prepared to handle the stressors of cancer.

Additionally, cancer survivors who were more recently in or out of cancer treatments were found to use adaptive coping strategies. This finding may be due to their need to cope with frequent treatment stressors (long and painful procedures). Independent *t*-tests revealed that survivors one year or less out of treatment used *emotional support*, *venting*, and *humor* in coping strategies more than survivors two or more years out of treatment. Overall, these findings are consistent with the theoretical conception of how coping is influenced by the individual's developmental stage and the current situation (Freydenberg, 2014). Survivors one year or less out of treatment are challenged with more cancer specific stressors (medical treatments, emotional stressor related to diagnosis) and have more support (family, friends, health professionals) readily available to them and they may have more a need to adjust/adapt to cancer as this is a new stressor in their life. In contrast, survivors further out of treatment may not utilize their support systems around them for the secondary stressors related to cancer treatment. Survivors further out from treatment may have adjusted to cancer stressors and there may be less cancer related stressors presently in their lives. More studies are needed in order to understand the complexity of coping at different ages with long treatment plans and ongoing adjustment to chronic illness.

### **Coping and Parental Care and Control.**

The parent-child relationship that develops in childhood continues to influence the child as they develop into an adult (Foster et al., 2011). Findings of the current study demonstrate the role of parental perception in coping of young and emerging adults. In the regression equation, both perception of maternal and paternal care were predictive factors to adaptive coping in this sample, highlighting the importance of these relationships. The findings are supported by previous research, where higher parental care was a factor associated with more adaptive coping

in individuals seeking university-counseling services (Buelow, Lyddon, & Johnson, 2002). Additionally, a partial correlation controlling for age and time since treatment demonstrated that higher levels of Maternal and Paternal Care were associated with lower levels of Maladaptive coping. This finding is concurrent with previous research, where Maternal Care was associated with a higher use of social support and a decrease in the use of maladaptive emotion-focused strategies in depressed adolescents (Matheson et al., 2005).

For some study participants, parent-child relationships were not reported to be high in Maternal Care but rather high in Maternal Control. During childhood, maternal control limits the child's ability to explore and become independent from their mothers (Schaefer, 1965). Perceived high Maternal Control may contribute to the individual's inability to develop age-appropriate sense of self and self-esteem (Sira & White, 2010), become independent as a person, and/or dependent upon his or herself (Schaefer, 1965). Participants in the study who reported higher levels of Maternal Control are also reported a higher use of maladaptive coping. According to the Double ABCX model, perceptions contribute to whether an individual views a stressor as manageable and unmanageable (McCubbin & Patterson, 1983). Thus, perceiving higher levels of Maternal Control the individual may not be able to perceive cancer as manageable stressor to them. Higher levels of Maternal Control may not provide the individual with the opportunity to develop their own effective coping strategies. These findings invite additional investigations on coping with chronic conditions where parental bonding should be investigated with regard to adaptive and maladaptive coping.

### **Coping and Spirituality.**

Spirituality has been investigated as one of the major factors contributing to coping in previous studies in chronic illnesses and in other cancer populations (Delago-Guay et al., 2011;

Lima et al., 2014; Schendier & Mannell, 2006; Sira et al., 2014; Speraw, 2006; Vespa, Jacobsen, Spazzafumo, & Balducci, 2011). While mothers coping with child's congenital heart defects (Sira et al., 2014) valued spirituality as a helpful tool in dealing with stressors in their lives, current study participants also incorporate this phenomenon into their coping. Despite that only 41.5 % of participants reported high emphasis on spirituality in this study, regression analysis revealed spirituality to be the strongest predictor of adaptive coping.

The results from this study suggest that higher levels of spirituality are related to more adaptive coping strategies in young adults. These findings are in congruence with previous research that has found spirituality to be associated with positive adaptive coping in other health conditions (Delago-Guay et al., 2011; Lima et al., 2014; Schendier & Mannell, 2006; Sira et al., 2014; Speraw, 2006; Vespa et al., 2011). Adaptive coping in the current study included the use of positive reframing and emotional and instrumental support from others. Therefore, the current results support the findings of Vespa, Jacobsen, Spazzafumo, and Balducci (2011) where individuals with spiritual beliefs used more adaptive coping strategies, such as thinking positively, expressing their emotions and having a support systems help with coping. Spirituality's contribution to coping could be the combination of seeking out meaning and purpose to life events, with the ability to find comfort and hope, and acceptance of the cancer diagnosis (Cavendish et al., 2004; Lima et al., 2013; Schendier & Mannell, 2006; Sira et al.; 2014; Speraw, 2006;).

## **Coping and Social Support**

Social networks such as friends, family members, and other cancer survivors have been a source of support and inspiration to cancer survivors (Zebrack et al., 2014). During cancer

treatments, pre-existing social networks are important support systems that the individual may rely on due to lack of energy and strength to form new connections (Miedema et al., 2007).

Therefore, it is important to recognize that one of the most discussed coping strategies by this population (in the open-ended responses) *was talking to, spending time with, or having support from their family, friends, and other cancer survivors.*

Within this population, the most important factors for support groups were connecting with survivors of a similar age ( $n=125$ , 59.5%), with survivors who were the same gender ( $n=115$ , 54.8%), and the same type of cancer ( $n=105$ , 50%). For survivors, who may lack friends and family support, connecting these individuals with support groups may be beneficial to their coping. Individuals can relate and discuss what they are feeling as well as create their own support network through treatments and survivorship. Survivors may feel that other young adult survivors understand their stressors better than friends and family. These finding is concurrent with previous research on young adult cancer survivors where friends, family, and other survivors have been found to be a source of support (Zebrack et al., 2014). Additionally, research has previously found positive/supportive social networks to assist with adaptive coping strategies (Miedema et al., 2007). The importance of social support in this study should be taken with caution as recruitment was done through online social media sites.

## **Limitations**

While the results of this study should be considered important to research on young adult cancer survivors, there are some limitations to the current study. The majority of the sample size was highly educated, White non-Hispanic, female cancer survivors. With limited male survivors represented in the study, it is difficult to generalize the results to male survivors' coping.

highlighting the need for further investigation with male survivors. In addition, the sample lacked racial diversity; it was primarily White non-Hispanic survivors. This limits the ability to generalize these results to young adults of different ethnicities and their coping abilities, but invites further investigation. These limitations may be due to recruitment through online social media sites and cancer forums. Despite the high use of technology and social media in society, there may be some emerging adult and young adult cancer survivors who may not have access to this technology. Individuals may not be able to afford technology because of other financial stressors. Recruitment from oncology clinics could allow for greater access to a more diverse sample of survivors.

The study used self-report methods for coping strategies. Some survivors were two or more years out of cancer treatments, therefore the coping strategies reported may not accurately represent strategies used by the individual later in life. Survivors further out from treatment may not be directly coping with cancer stressors. Additionally, the Brief COPE scale (Carver et al., 1997) describes a limited number of coping strategies and some strategies used by individuals may not be represented in the scale.

## **Clinical Recommendations**

The understanding of emerging and young adults coping strategies is essential in order to better prepare clinicians to work with these populations. Clinicians need to recognize that emerging adults may not be able to cope as effectively as young adults. Taking into account the different developmental stressors related to age could provide insight into different pile-up stressors for emerging adults compared to young adults. Thus, the knowledge of human developmental milestones (tasks for emerging adults), development related stressors should be

widely discuss in medical community in order to provide better medical care and create a healing environment for the transition to adult medical care. Specifically, having a developmental specialist on the healthcare team would allow for developmental needs to be appropriately addressed. The developmental specialist could provide educational trainings for other healthcare professionals on the unique needs of this age group.

While parental influences become less apparent during young adulthood, the clinicians also need to recognize the young adult's relationships with their parents, as family support is essential in coping with cancer. Therefore, the counselor or family therapist may need to help create or rebuild positive relationships within the family. Particularly, focusing on the young adult's ability to effectively communicate with family members. However, if it is not possible to repair poor relationships with the family members, clinicians may want to look for ways to connect young adults with survivors with characteristics similar to the individual, for example connecting the survivor with support groups that they can relate to (i.e. young adult cancer support groups or support groups for their particular cancer).

Lastly, health care professionals working with this population should be aware that spirituality is an important factor/resource for young adult's coping. Healthcare professionals should recognize and be aware of the individual's spiritual beliefs during treatments. Educating healthcare team members including hospital chaplains on diversity in spiritual beliefs would allow for creating of more inclusive and healing environment for those who cope with variety of stressors and serious health conditions.

## **Recommendations for Further Research**

While more research will be needed to understand the complexity of coping in this population, special attention is required to investigate coping in male population in order to develop new and effective ways to support cancer survivors and their families. For future research attempts, perhaps, recruitment from oncology clinics could help to increase in the numbers of male survivors as well as increase participation of survivors from other ethnicities. For an increase in male recruitment, researchers may want to recruit social media site focusing on more specific male cancers. If recruitment is done through online social media, researchers should ensure online surveys are cell-phone friendly as the majority of individuals accessing social media sites (Facebook and Twitter) via cell-phones.

In addition to recruiting more diverse young adult cancer survivors, future researchers could investigate additional factors that contribute to adaptive and maladaptive coping. Given the fact that the current study found significant associations between parental care and control and coping, researchers should further investigate this relationship by specifically researching attachment styles and its association on coping and resilience as internal individual resources. Maladaptive coping strategies and lack of family support should also be a warning sign and should be addressed and investigated further.

The present study found differences in coping between survivors more recently in treatments compared to survivors further out of treatment. Further investigation is needed to better understand why more recent young adult survivors are coping better than survivors further out of treatment.

Finally, more research is needed to understand spirituality's role in young adults with chronic health conditions. Particularly, there is a need to investigate how young adults use spirituality during cancer treatments and survivorship. Future researchers could extend this research by investigating by evaluating spirituality at different stages in the cancer treatment to better understand spirituality's role during and after cancer treatment.

## **Conclusions and Implications**

Cancer is a prolonged chronic disease therefore there is a need to understand how individuals live with this disease after treatment in order to help those who deal with the life-long effects of cancer. Although this study highlighted and described coping strategies with cancer in emerging adult and young adult populations indicating a few components (spirituality, maternal/paternal care) that contribute to adaptive coping, there is still a need for more research in this population. Understanding predominant coping styles will help healthcare professionals to better support emerging and young adults in their coping with this disease. Additionally, this knowledge will lead to better ways to support families with newly diagnosed family members. The effects of cancer treatments affect young adult cancer survivors, whether it is the late effects of treatments or the emotional/psychological effects of the uncertainty that comes with surviving cancer. Therefore, more knowledge is needed to prepare younger adults to cope with these challenges and to prepare/educate multi-disciplinary medical team about coping in this age group. Further knowledge would allow multi-disciplinary medical teams to be able to recognized maladaptive coping strategies among their patients and guide them to adaptive positive behavior.

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## APPENDIX A: ECU UMCIRB APPROVAL LETTER



**EAST CAROLINA UNIVERSITY**  
**University & Medical Center Institutional Review Board Office**  
4N-70 Brody Medical Sciences Building· Mail Stop 682  
600 Moye Boulevard · Greenville, NC 27834  
Office [252-744-2914](tel:252-744-2914) · Fax [252-744-2284](tel:252-744-2284) · [www.ecu.edu/irb](http://www.ecu.edu/irb)

### Notification of Initial Approval: Expedited

From: Social/Behavioral IRB  
To: [Cameron Foster](#)  
CC: [Natalia Sira](#)  
[Natalia Sira](#)  
Date: 4/1/2015  
Re: [UMCIRB 15-000356](#)  
Young Adult Cancer Survivors: Exploring attachment style, coping, and spirituality

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 4/1/2015 to 3/31/2016. The research study is eligible for review under expedited category # 7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
Demographic Questions	Data Collection Sheet
Informed Consent	Consent Forms
Recruitment Announcement	Recruitment Documents/Scripts
Survey	Surveys and Questionnaires
Thesis Proposal	Study Protocol or Grant Application

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

## **APPENDIX B: INFORMED CONSENT FORM**

Dear Participant,

You are being asked to participate in a research study that is being conducted by Cameron Foster, who is a master's degree candidate at East Carolina University. This questionnaire should not take longer than 20 minutes to complete. You will not be at physical or psychological risk and should not experience stress from participating. Participation is voluntary and you may withdraw by ending the survey at any time without consequences. The information you provide will not be linked to you and will be completely confidential. Therefore, your responses cannot be traced back to you by anyone, including me. This research was approved by the ECU Institutional Review Board. If you have questions about your rights when taking part in this research, call the Office of Research Integrity & Compliance (ORIC) at phone number 252-744-2914 (weekdays, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you can call the Director of ORIC, at 252-744-1971. The study number is UMCIRB 15-000356 By clicking "I agree to participate", you agree that you have read and understood this consent form and are willingly agree to participate in this study.

Sincerely,

Cameron Foster, MS candidate, ECU

fosterc13@students.ecu.edu

Principal Investigator

- I agree to participate
- I do not agree to participate

## **APPENDIX C: THESIS SURVEY TOOL**

Q2.1 Please tell us about yourself.

Q2.2 What is your gender?

- Male
- Female

Q2.3 What is your age?

- 18
- 19
- 20
- 21
- 22
- 23
- 24
- 25
- 26
- 27
- 28
- 29
- 30
- Other \_\_\_\_\_

Q2.4 How do you identify your race or ethnicity?

- White or Caucasian
- Black or African American
- Hispanic or Latino
- Asian American
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Island
- Multi Racial
- Other: Please Specify \_\_\_\_\_

Q2.5 What is your marital status?

- Single
- Married
- Divorced
- Widowed
- Separated

Q2.6 What is your current level of education?

- Some High School
- High School Diploma
- Some College
- Associates Degree
- Bachelors Degree
- Professional Degree
- Masters Degree
- Doctoral Degree

Q2.7 What is your religious background?

- Christian
- Jewish
- Muslim
- Buddhist
- Unitarian/Universalist
- Hindu
- Native American
- Spiritualist
- Other \_\_\_\_\_

Q2.8 Did you live with both your parents growing up?

- Yes
- No
- My parents divorced

Q2.9 Who did you live with growing up?

- Mother and Stepfather
- Father and Stepmother
- Mother Only
- Father Only
- Grandparents
- Grandmother Only
- Grandfather Only
- Other \_\_\_\_\_

Q3.1 Please tell us about your experience with cancer.

Q3.2 At what age were you diagnosed with cancer?

Q3.3 How long has it been since you have received active cancer treatments?

- Currently undergoing treatment
- less than 1 year
- 1 year
- 2 years
- 3 years
- 4 years
- 5 years
- 6 years or more

Q3.4 Have you ever had a relapse?

- Yes
- No

Q3.5 Have you had a secondary cancer?

- Yes
- No

Q3.6 Who was your primary caregiver during treatments?

- Mother
- Father
- Sibling
- Significant Other or Spouse
- Friend
- Other \_\_\_\_\_

Q5.1 Since being diagnosed with cancer, please reflect on how often you have found yourself engaging in the following activities. Please read each item separately and rate how each item applies to you personally.

	I haven't been doing this at all (1)	I've been doing this a little bit (2)	I've been doing this a medium amount (3)	I've been doing this a lot (4)
I've been turning to work or other activities to take my mind off things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been concentrating my efforts on doing something about the situation I'm in.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been saying to myself "this isn't real."	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been using alcohol or other drugs to make myself feel better.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I've been getting emotional support from others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been giving up trying to deal with the cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been taking action to try to make the situation better.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been refusing to believe that cancer has happened.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been saying things to let my unpleasant feelings escape	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been getting help and advice from other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been using alcohol or other drugs to help me get through the cancer diagnosis.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I've been trying to see it in a different light, to make cancer seem more positive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been criticizing myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been trying to come up with a strategy about what to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been getting comfort and understanding from someone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been giving up the attempt to cope.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been looking for something good in what is happening.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been making jokes about cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	○	○	○	○
I've been accepting the reality of the fact that cancer has happened.	○	○	○	○
I've been expressing my negative feelings.	○	○	○	○
I've been trying to find comfort in my religion or spiritual beliefs.	○	○	○	○
I've been trying to get advice or help from other people about what to do.	○	○	○	○
I've been learning to live with cancer.	○	○	○	○

I've been thinking hard about what steps to take.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been blaming myself for things that happened.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been praying or meditating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been making fun of the situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.1 Please reflect on the importance of spirituality during your cancer diagnosis and treatments.

	Agree (2)	Neutral (1)	Disagree (0)
Spirituality should be part of holistic care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel comfortable if/when my family or friends ask me to pray or meditate with them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I view spirituality as an important part of my healing process.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I understand my own spirituality and personal beliefs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

My personal beliefs and spirituality are my main sources from which I receive hope, strength, comfort, and peace.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All human beings are spiritual in some form.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my own personal journey toward spiritual fulfillment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.2 What aspects of your spirituality do you find most helpful to you? (Mark all that apply)

- Prayer, meditation
- Reading scripture
- Listening to music
- Being in nature
- Religious services
- Exercise or pampering
- Other \_\_\_\_\_

Q4.1 Please reflect on your relationship with your mother

Q37 Has your mother been supportive since your cancer diagnosis?

- Yes
- No

Q4.2 As you remember your MOTHER or MOTHER FIGURE in your first 16 years would you place a tick in the most appropriate box next to each question.

	Very Like (1)	Moderately Like (2)	Moderately Unlike (3)	Very Unlike (4)
Spoke to me in a warm and friendly voice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did not help me as much as I needed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Let me do those things I liked doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seemed emotionally cold to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appeared to understand my problems and worries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was affectionate to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Liked me to make my own decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did not want me to grow up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried to control everything I did	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Invaded my privacy	○	○	○	○
Enjoyed talking things over with me	○	○	○	○
Frequently smiled at me	○	○	○	○
Tended to baby me	○	○	○	○
Did not seem to understand what I needed or wanted	○	○	○	○
Let me decide things for myself	○	○	○	○
Made me feel I wasn't wanted	○	○	○	○
Could make me feel better when I was upset	○	○	○	○
Did not talk with me very much	○	○	○	○
Tried to make me feel dependent on her	○	○	○	○
Felt I could not look after myself unless she was around	○	○	○	○

Gave me as much freedom as I wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Let me go out as often as I wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was overprotective of me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did not praise me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Let me dress in any way I pleased	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6.1 Please tell us what other helpful ways to cope.

Q6.2 What are or were other helpful ways to cope during cancer treatments?

Q6.3 What are or were other helpful ways to cope after cancer treatments?

Q35 What else should be known about dealing with cancer as a young adult?

Q6.4 Do you attend any support groups in person?

- Yes
- No
- No, I have in the past.
- No, I would if I could find one in the area I live.

Q6.5 Having support from a survivor with the same cancer as me is important.

- Yes
- No
- I just prefer to have support from other cancer survivors, regardless of their cancer diagnosis

Q6.6 Connecting with survivors of the same gender as me is important.

- Yes
- No

Q6.7 I prefer to connect with survivors around my age

- Yes
- No
- I haven't been able to connect with survivors around my age but I would like to.

Q39 Please reflect on your relationship with your father.

Q38 Has your father been supportive since your cancer diagnosis?

- Yes
- No

Q4.3 As you remember your FATHER or FATHER FIGURE in your first 16 years would you place a tick in the most appropriate box next to each question.

	Very Like (1)	Moderately Like (2)	Moderately Unlike (3)	Very Unlike (4)
Spoke to me in a warm and friendly voice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did not help me as much as I needed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Let me do those things I liked doing	○	○	○	○
Seemed emotionally cold to me	○	○	○	○
Appeared to understand my problems and worries	○	○	○	○
Was affectionate to me	○	○	○	○
Liked me to make my own decisions	○	○	○	○
Did not want me to grow up	○	○	○	○
Tried to control everything I did	○	○	○	○
Invaded my privacy	○	○	○	○
Enjoyed talking things over with me	○	○	○	○
Frequently smiled at me	○	○	○	○
Tended to baby me	○	○	○	○

Did not seem to understand what I needed or wanted	○	○	○	○
Let me decide things for myself	○	○	○	○
Made me feel I wasn't wanted	○	○	○	○
Could make me feel better when I was upset	○	○	○	○
Did not talk with me very much	○	○	○	○
Tried to make me feel dependent on him	○	○	○	○
Felt I could not look after myself unless he was around	○	○	○	○
Gave me as much freedom as I wanted	○	○	○	○
Let me go out as often as I wanted	○	○	○	○
Was overprotective of me	○	○	○	○

Did not praise me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Let me dress in any way I pleased	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q8.1 Thank you for your time! The survey has ended. Should you have any questions or concerns about the nature of this study please feel free to contact the Principle Investigator, Cameron Foster at [fosterc13@students.ecu.edu](mailto:fosterc13@students.ecu.edu) or you can the East Carolina University's Office of Research Integrity & Compliance (ORIC) at 252-744-2914 (weekdays, 8:00am - 5:00pm). If you would like to report a complaint or concern about this research study, please call the Director of ORIC at 252-744-1971. The study number is UMCIRB-15-000356