ADOLESCENT AND YOUNG ADULT ROMANTIC RELATIONSHIPS AND CANCER: COMPARING PATIENT AND PARTNER

A Thesis Presented to
The Faculty of
The College of Arts and Sciences
Ohio University

In Partial Fulfillment
of the Requirements for Graduation
with Honors in Psychology

By
Leah V. Cornish
May 2014
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**Abstract**

While it is well documented in the literature that older adult marital relationships are impacted by a cancer diagnosis, it is largely unknown how adolescent and young adult romantic relationships (AYA) are affected by cancer. The current study explored how a cancer diagnosis may impact AYA romantic relationships by assessing patients and partners in three different areas: relationship satisfaction, emotional well-being, and identity. A sample of eight AYA patients and partners completed an online survey to evaluate their experience in these three domains. The study found that AYA cancer patients and survivors have more trust in their partner than do the partners of cancer patients. It was also noted that treatment intensity was viewed to be more intense by partners than by the patients and survivors who experienced them directly. Lastly, the study found that AYA cancer patients have a lower identity achievement than partners. No differences were discovered in emotional well-being between patients and partners, and with such a small sample gender differences were unable to be explored. While the sample of this study was too small to statistically test many potential differences, the results suggest that future research and interventions for AYA couples coping with cancer may benefit from focusing on building and maintaining trust, especially for those experiencing more intense treatments, and also recognize that AYA cancer patients may need help in maintaining or defining their identity.
Adolescent and young adult romantic relationships and cancer:

Comparing patient and partner

A cancer diagnosis is a life-altering experience that affects the patient physically, mentally, and emotionally; however, it is not only transformative for the patient, but for the family and friends of the patient, and especially their significant other or spouse. While the number of cases of cancer diagnosed among adolescents and young adults (AYAs) aged 15-39 is more than six times greater than in children 14 and under, significantly less attention has been given to AYAs. In 2011, 69,212 AYA’s in the U.S. were diagnosed with cancer (National Cancer Institute, 2014). Despite the greater numbers, the decreased attention given to AYA cancer diagnoses has led to decreased scientific research and created a disproportionately low improvement in survival rates and outcomes when compared to both children and older adult cancer diagnoses (University of Southern California, 2014). This gap in scientific research also extends to psychological research on AYA cancer patients.

While it is well demonstrated in the literature that older adult romantic relationships are impacted by a cancer diagnosis (Ben-Zur, 2001; Braun et al., 2007; Giese-Davis, Hermanson, Koopman, Weibel & Spiegel, 2000; Hagedoorn, Sanderman, Bolks, Tuinstra & Coyne, 2008; Hannah et al., 1992; Manne & Badr, 2008; Manne, Badr, Zaider, Nelson & Kissane, 2010; Northouse, Templin, Mood & Oberst, 1998), adolescent and young adult romantic relationships have not been studied adequately. Modeling our study off of the current very limited literature on AYA romantic relationships during cancer and the much more abundant literature on
older adult relationships, we decided to focus on three main components of romantic relationship functioning: relationship satisfaction, emotional well-being, and identity.

In addition to these three main elements, we also examined the effect of gender differences and perceived treatment intensity.

**Relationship Satisfaction**

Studies examining relationship satisfaction in couples facing cancer found that the diagnosis could have a relationship strengthening effect or a relationship weakening effect. One study comparing testicular cancer survivors and Hodgkin’s disease survivors and their spouses (testicular cancer patient mean age 37.7, spouse mean age 35.6; Hodgkin’s disease mean age 35.2, spouse mean age 34.3) found that regardless of the diagnosis, the majority of the couples reported that the cancer experience had a relationship-strengthening effect, drawing them closer together (Hannah et al., 1992). However, a small portion, about 20 percent of couples reported that the cancer diagnosis and treatment had negatively impacted their relationship, creating a wedge between patient and spouse. One of the most important factors in maintaining relationship satisfaction was communication. While patients reported an increase in couple communication during treatment, and no change afterwards, spouses reported a decrease in couple communication during and an increase after treatment completion. Spouses often reported “protecting” their partner from their fears and concerns about the disease by avoiding communicating these worries to the patient, leading to decreased communication, and consequently to lower relationship satisfaction (Hannah et al., 1992). This finding was also demonstrated by another
Another study researched the impact of testicular cancer on romantic and sexual relationships in AYA patients only (age ranging from 18 to 34 years, mean age 27.1 years) (Carpentier, Fortenberry, Ott, Brames & Einhorn, 2011). This study found that there are four recurring themes related to testicular cancer diagnosis that influence satisfaction in romantic relationships: embarrassment leads to delays in care-seeking, testicular cancer makes you feel different from others, being different from others makes you feel as though you are damaged goods, and cancer disclosure is difficult. These four themes illustrate how the AYA testicular cancer patient is changed by the diagnosis, affecting his romantic and sexual relationships. With regard to feeling different from others, patients who were unpartnered at the time of their diagnosis and treatment thought the experience impacted them in a negative way, making them worry about how future partners will respond. However, those that were partnered during their diagnosis and treatment thought that the experience had changed them for the better, helping them grow up and see what was truly important to them in life. This may suggest that for any AYA cancer diagnosis, romantic partner support has a buffering effect, turning a negative experience into a positive one for the patient. Although this study examined only patients with testicular cancer, these findings may be applicable to other adolescent cancer diagnoses. It may not be that specifically testicular cancer makes you feel different from others, but simply having cancer of any
kind as an adolescent or young adult makes you feel different from others. The latter two of the four themes may also apply to any AYA cancer patient. Another study revealed that adolescent cancer survivors (ages ranging from 16 to 22 years, mean age 19 years 11 months) reported that their experience with cancer strengthened their relationships with family and friends, which may also suggest that an AYA cancer diagnosis would strengthen romantic relationships, increasing relationship satisfaction (Wicks & Mitchell, 2010). No previous studies have compared adolescent and young adult cancer patients and their partners with regard to relationship satisfaction. The current study evaluated relationship satisfaction of cancer patients and partners of cancer patients and directly compared them to see how each group is affected by the cancer diagnosis.

One study on older (ages ranging from 32 to 69, patient mean age 53, partner mean age 54) married and cohabitating couples dealing with a cancer diagnosis found that there are certain behaviors in which couples engage that enhance the relationship, and certain behaviors that compromise the relationship. Couples who engage in relationship enhancing behaviors like reciprocal self-disclosure, partner responsiveness, and relationship engagement (e.g. telling your partner about your feelings, responding to your partner’s needs) tend to score higher on relationship satisfaction than those who engage in relationship compromising behaviors like avoidance, criticism, and pressure-withdraw behaviors (e.g. partner pressuring the patient to talk about the diagnosis when he or she is not ready; Manne & Badr, 2008). Another study of prostate cancer patients and their partners (patient mean age 59.9,
partner mean age 53.3) found that holding back their fears of disease progression or
death led to greater distress and reduced intimacy in the relationship (Manne et al.,
2010). These studies have illustrated that many factors impact relationship
satisfaction, including communication (Hannah et al., 1992; Giese-Davis, et al., 2000)
or lack thereof (Manne et al., 2010) and certain behaviors (Manne & Badr, 2008). The
current study evaluated romantic relationship satisfaction in AYA cancer patients and
partners of AYA cancer patients and compared them to see how relationship
satisfaction is impacted by relationship role (i.e., patient or partner).

**Emotional Well-Being**

Studies comparing older adult patients and partners on emotional well-being
and distress have yielded conflicting results. Some studies claim that the patient
experiences more distress and has lower emotional well-being compared to the partner
(Ben-Zur, 2001; Giese-Davis et al., 2000; Northouse et al., 1998). Northouse and
colleagues (1998) compared women with breast cancer and their husbands to women
with benign breast disease and their husbands (mean ages 46-53). Results suggested
that even after one year, couples in the malignant group had a lower emotional well-
being than those in the benign group, with the patients experiencing greater distress
than their spouses. Another study on breast cancer patients and their husbands (patient
mean age 52.24 years, spouse mean age 55.60 years), found that partner coping style
is related to patient emotional well-being and vice versa. Certain patient and partner
coping strategies like ventilation, denial, religion, and emotional or behavioral
disengagement had a negative effect on their spouse, while problem-focused coping
like planning and active coping actually enhanced their spouse’s emotional well-being (Ben-Zur, 2001). The first set of coping styles was more likely to be used by spouses of breast cancer patients than the patients themselves, leading to lower emotional well-being in patients.

In contrast to the previously mentioned studies on cancer patient and partner emotional well-being, another study found that partner caregivers experience greater distress and lower emotional well-being than patients (patients range in age from 28 to 81 years, mean age 61.8 years; partners range in age from 31 to 80 years, mean age 60.0 years; Braun et al., 2007). The researchers found that, for spousal caregivers of advanced cancer patients, about 40% of caregivers report depressive symptoms, nearly twice the amount as patients. These findings were partially attributed to attachment style: those partners who were anxiously attached experienced the highest rates of depression, and those partners with avoidant personality characteristics experienced more depression than other personality types. Together, these studies show that it is unclear whether cancer patients or their partners experience greater distress and lower emotional well-being as a result of the diagnosis and treatment. The current study evaluated emotional well-being in an AYA sample.

**Identity**

In the literature, identity can be defined in two different ways; it can be the level of personal development achieved by an individual, as in Madan-Swain and colleagues’ 1999 study, or it can be the way a person sees him or herself, as in Song and colleagues’ 2012 study. A cancer diagnosis can impact both of these identity
constructs. Previous studies have shown that identifying as a cancer patient can have positive and negative effects (for review, see Harwood & Sparks, 2003). Positive effects include joining together with other cancer patients for social support, greater attention to health behaviors and compliance with treatment regimens leading to better health outcomes. Negative effects include believing the cancer is an intrinsic part of the self, leading to a feeling of reduced control. This self-stereotyping has a great deal to do with the patient’s preconceived idea of what it means to be a cancer patient. For example, if the imagined prototypical cancer patient is an empowered survivor, they are likely to identify positively, and if their prototypical cancer patient is terminal, they are likely to negatively identify. One study found that long-term survivors of childhood cancer (ages ranging from 18 to 29 years) have demonstrated that both negative and positive stereotypes of cancer patients become part of a survivor’s identity, impacting emotional well-being (Song et al., 2012). By examining video narratives expressing their feelings and self-report data assessing the survivors’ identity, this study also found that cancer survivors’ identity is impacted by the stereotypical cancer patient they imagine. Childhood cancer survivors who report internalizing positive stereotypes like strength and bravery report higher self-efficacy, and those who report internalizing negative stereotypes report lower self-worth.

Based on James Marcia’s theory of adolescent identity formation, there are four stages of ego-identity development: achievement, moratorium, foreclosure, and diffusion (Marcia, 1966). The highest level of identity development, achievement, is characterized by extensive exploration and a high level of commitment. The next level
below achievement is called moratorium, and refers to a period of actively experiencing an identity crisis, exploring options but not yet arrived at a conclusion. The next lowest stage is called foreclosure and is characterized by taking on the views of trusted adults rather than forming one’s own beliefs; individuals at the foreclosed identity status have made a strong commitment to a certain position without much consideration of alternatives. Identity diffusion, the lowest level of identity development, refers to the period of development when a child has not yet made any ideological commitments or felt a need to establish his or her own identity (Marcia, 1966; Adams, Bennion and Huh, 1989). Previous research has explored the ego-identity development of adolescent survivors of childhood cancer. When compared to healthy counterparts, adolescent survivors of childhood cancer (ages ranging from 12 to 23 years, mean ages 16.75 and 17 years, respectively) shows that cancer survivors are more likely than the healthy counterparts to be in the identity foreclosure stage (Madan-Swain et al., 1999). The healthy counterparts were more likely to have attained the identity achievement status, the highest level of identity formation. These studies show that a cancer diagnosis can negatively or positively impact the way a person identifies (Harwood & Sparks, 2003; Song et al., 2012) and can also impact ego-identity status (Madan-Swain et al, 1999).

While research on the identity formation of cancer patients and survivors has shown that identity depends largely on their preconceived notion of what it means to be a cancer patient, no studies to date have shown how social identity of partners may be impacted by the diagnosis. The diagnosis could affect how the partner identifies,
possibly changing his or her identity from significant other or spouse to caregiver. Additionally, no known previous studies have examined the impact of changing identity on a romantic relationships. Because a cancer diagnosis can change the way a person views themselves, their self-identity, this may affect their romantic relationship. The current study examined two different applications of identity in each participant: the ego-identity status and the self-identity. Patient and partner were compared to see how role impacts identity in AYA romantic relationships.

**Additional Factors**

As well as the three main factors that potentially impacted AYA romantic relationship functioning during cancer, two additional factors may also influence the relationship: gender and treatment intensity. With regard to gender, one study found that regardless of patient or partner role, females experience lower emotional well-being than males, illustrating the need to examine gender differences (Hagedoorn et al., 2008). Hagedoorn and colleagues (2008) claim that females experienced greater distress and lower emotional well-being for a variety of reasons. First, women generally see themselves as a nurturer, so if they are unable to comfort an ill partner it is distressing to them, or if they are the patient, their illness may prevent them from taking care of their spouse, also creating distress. Additionally, females are more reactive to their partner’s stresses, contributing to distress in the cancer experience whether they are the patient or the partner. Therefore gender differences were also examined in the current study.
Another factor potentially linked to relationship satisfaction in AYA cancer patients is treatment intensity. In adolescent survivors of childhood cancer (mean age 21.61), treatment intensity was inversely related to relationship satisfaction, with those that had more intense treatments experiencing lower relationship satisfaction (Thompson, Marsland, Marshal & Tersak, 2009). Consequently, perceived intensity of treatment was measured in the current study to determine the effect it has on AYA patients and partners and their romantic relationship.

Summary

Research on AYA cancer experiences emphasizes the importance of romantic relationships (Zebrack, 2011). Although many studies highlight the substantial impact significant others have on AYA cancer patients, none adequately explain how the significant other affects the patient’s experience or how the partner is affected by their significant other’s diagnosis (Carpentier et al., 2011). Therefore, it is unknown how romantic relationships impact the AYA cancer experience, or how a cancer diagnosis in adolescence or young adulthood impacts romantic relationships.

Specific Aims

The aim of the current study was to examine the effect of relationship role (patient or partner) on relationship satisfaction and intimacy, social identity, and emotional well-being in adolescent and young adult (AYA) couples in which one member has experienced a cancer diagnosis. The available literature on the romantic relationships of cancer patients and their partners focused almost entirely on older adult relationships. AYA relationships differ from older adult relationships in several
ways, so the results of these studies may or may not have applied to the AYA relationship. AYA couples are obviously younger, but they are also less likely to be married, and unlike married couples, the relationships may or may not be sexual.

Many previous studies emphasized sexual satisfaction and frequency as a means to evaluate the marital relationship, but since AYA couples may or may not be married or sexually active, this measure may not be meaningful in young couples. The current study examined AYA romantic relationships in which one partner had been diagnosed with cancer to see how patient and partner are affected individually, and how they perceive the relationship had been impacted by the cancer diagnosis.

**Hypotheses and Research Questions**

For this study, there was one primary hypothesis, two primary research questions, and two secondary hypotheses. For our first primary hypothesis, we predicted that partner emotional well-being (as measured by self-report quality of life and positive and negative emotions) would be greater than patient emotional well-being. Based on previous research, we expected to find that partner emotional well-being would be greater than patient emotional well-being due to the fact that the patient undergoes treatment and the partner does not. For our secondary hypotheses, we predicted that male emotional well-being would be greater than female emotional well-being, and relationship satisfaction will decrease as perceived treatment intensity increases. For the first primary research question, we examined the effect of relationship role (patient or partner) on relationship satisfaction and intimacy: do patients or partners report greater satisfaction and intimacy? As our second primary
research question, we examined the effect of relationship role (patient or partner) on identity: do patients or partners report greater impact on identity?

Methods

Participants

Participants were recruited in three separate ways: through various cancer-related websites (e.g. www.stupidcancer.org, www.lls.org, etc.), through contacting personal and professional contacts of the researcher, and through Mechanical Turk (MTurk), mturk.com, an online crowd-sourcing site through amazon.com. Participants were recruited from March to May of 2014. The participants were English-speaking, American AYA cancer patients and partners aged 15 to 39 at the time of diagnosis and 18 or above at the time of survey. Of the 25 participants who followed the link, 15 met the inclusion criteria and consented to participate, and of those, eight completed the survey in its entirety. Four of the participants (50%) were recruited through mturk.com, three (37.5%) from the cancer websites, and one (12.5%) through direct email from the researcher. Seven of the eight participants were female (87.5%). Of the eight participants, three patients or their partners experienced breast cancer (37.5%), and the remaining five (12.5% each) experienced melanoma, Acute Lymphocytic Leukemia (ALL), prostate cancer, glioblastoma, and nasopharyngeal cancer. Three participants (37.5%) were cancer patients or survivors (all female) and five (62.5%) were romantic partners of cancer patients or survivors (one male and four female).
**Procedure**

On MTurk, requestors (researchers) post jobs that they refer to as “HITs,” which are completed by workers (participants) for compensation. The requestor is anyone who uploads a job, in this case a survey, and the workers are the people who complete the job. Participants who followed the link to the survey from any of the three recruitment methods completed the informed consent process and after agreeing to participate they were asked to complete an online survey through qualtrics.com. The survey, which measured each participant’s emotional well-being, relationship satisfaction, identity, and cancer history, took approximately 30 minutes to complete. Use of these websites allowed the researcher to survey a unique population that would otherwise be very difficult to study at Ohio University. Participants recruited through MTurk were compensated $1.00 for their participation and those recruited through cancer websites and through personal and professional connections of the researcher were entered into a raffle to win one of two $50 Visa gift cards.

**Measures**

**Pre-Consent Eligibility Criteria (Appendix A).** A pre-consent questionnaire was administered to confirm that participants meet eligibility criteria for the survey (i.e., at least 18 years old, residing in the United States, cancer survivor or patient diagnosed between the ages of 15-39, or the partner or spouse of a cancer patient or survivor diagnosed between the ages of 15-39).
Demographics (Appendix B). Participants were asked to answer several questions about their demographics (i.e., age, gender, race/ethnicity, marital status etc.).

Cancer History (Appendix C). Participants completed several questions about the cancer history, either their own or their partner’s (i.e., cancer type, age of patient’s diagnosis, type of treatment(s), perceived treatment intensity, length of treatment etc.). The participants were asked to complete the Assessment of Life Threat and Treatment Intensity Questionnaire (ALTTIQ; Stuber, Kazak, Meeske, Barakat, Guthrie, Garnier, Pynoos & Meadows, 1997). The ALTTIQ is a seven-item questionnaire which evaluates perceived cancer treatment intensity and fear of death. This measure was associated with greater anxiety and posttraumatic stress symptoms in childhood cancer survivors between the ages of 8 and 20, demonstrating construct validity (Stuber et al., 1997). In the present study, wording of the questions was slightly altered so it makes sense for both patients and partners (i.e. “your diagnosis” was changed to “your/ your partner’s diagnosis”). Participants respond to statements (e.g. “I/My partner had a lot of cancer treatments.”) using a 5-point Likert scale ranging from 1 = disagree to 5 = agree. Higher scores represent more intense cancer treatments. The Cronbach’s alpha for the overall score of the Assessment of Life Threat and Treatment Intensity Questionnaire (ALTTIQ) was acceptable, with $\alpha = .72$.

Relationship Satisfaction. Participants were asked to complete the Perceived Relationship Quality Components inventory (PRQC) to evaluate relationship satisfaction (Fletcher, Simpson & Thomas, 2000). The PRQC is an 18-item self-report
questionnaire that evaluates six components of relationship quality (satisfaction, commitment, intimacy, trust, passion, love), with three questions for each of the six components. The PRQC has good internal reliability and results correspond to other measures of relationship quality (Fletcher et al., 2000). Participants responded to each statement on a 7-point rating scale ranging from 1 = not at all to 7 = extremely. Higher scores indicated greater relationship quality. We used the overall score, as well as the trust and intimacy subscale scores of the PRQC to evaluate relationship satisfaction. Results of Cronbach’s alpha for the PRQC overall score was excellent (α = .95), while the intimacy subscale internal consistency was good (α = .86), and the trust subscale was acceptable (α = .74).

**Emotional Well-being.** Emotional well-being was evaluated using two different measures, the Quality of Life-Cancer Survivors inventory (QOL-CS; Ferrell, Dow and Grant, 1995), which is for specifically cancer-related emotional well-being, and the Positive and Negative Affect Schedule-Expanded form (PANAS-X; Watson & Clark, 1999), which is a more general measure of emotional well-being. The overall scores from the QOL-CS and the PANAS-X were used to evaluate participants’ emotional well-being. The QOL-CS is a 41-item questionnaire that evaluates five different components of well-being: physical, psychological, spiritual, and social. Participants answered the questions on an 11-point rating scale ranging from 0 (worst outcome) to 10 (best outcome); some items were reverse-scored. Higher scores indicated greater quality of life. Wording of the questions was slightly altered so it makes sense for both patients and partners (i.e. “your diagnosis” was changed to
“your/ your partner’s diagnosis”). Questions in the social component were changed to measure support from the romantic partner (i.e. “How distressing has the illness been for your family?” was changed to “How distressing has the illness been for your partner?”). In past research, the QOL-CS showed expected associations with other established measures of quality of life and has good construct validity (Zebrack, 2011). For the Quality of Life- Cancer Survivors (QOL-CS) inventory, the overall score of Cronbach’s alpha was excellent (α = .95).

The PANAS-X is a 60-item self-report survey of mood, examining 11 different specific emotions—fear, sadness, guilt, hostility, shyness, fatigue, surprise, joviality, self-assurance, attentiveness and serenity—which are combined to yield two scores, one for positive emotions and one for negative emotions. Participants were asked to indicate how often they have felt each emotion in the past few weeks, using a 5-point rating scale ranging from 1 (very little or not at all) to 5 (extremely). The PANAS-X has good construct validity and is highly correlated with another accepted mood inventory, the Profile of Mood States (POMS; McNair, Lorr & Droppleman, 1971). Cronbach’s alpha test of internal consistency for both the positive (α = .93) and negative (α = .98) affect scales was excellent.

The Life Orientation Test- Revised (LOT-R; Scheier, Carver, & Bridges, 1994) was used to evaluate optimism. The LOT-R is a widely used 10-item self-report questionnaire measuring the optimistic disposition. Participants responded to each statement (e.g. “If something can go wrong for me, it will.”) on a 5-point Likert scale ranging from 1 = “I agree a lot” to 5 = “I disagree a lot.” Scores were summed, with
higher scores reflecting greater optimism. Past research indicates that the LOT-R has good construct validity and positively correlates with measures of psychological well-being (e.g., Scheier & Carver, 1992). In the present study, the overall score of internal consistency for the Life Orientation Test- Revised (LOT-R) was good, with $\alpha = .80$.

**Identity.** Two measures of identity were used: The Who Am I? Test (Kuhn & McPartland, 1954) and the Objective Measure of Ego-Identity Status (OMEIS; Adams, Bennion and Huh, 1989). These two measures were used to measure two different types of identity. Achievement of identity status was measured by the OMEIS and self-perceived social identity was measured by the Who Am I? Test. The OMEIS is a 24-item self-report measure of identity status. Participants responded to each statement (e.g. “I just can’t decide what to do for an occupation. There are so many possibilities.”) on a 6-point Likert-type scale ranging from strongly agree (1) to strongly disagree (6). Higher scores reflect higher identity achievement. The overall score on the OMEIS was used to determine the identity status of each participant. Overall internal consistency of the OMEIS as measured by Cronbach’s alpha was good, with $\alpha = .86$.

The Who Am I? Test is an open-ended exercise where participants are asked to take one minute and type as many (up to 20) words or phrases that describe themselves. Number of words related to cancer patient/survivor or caregiver status (i.e., sick, dependent, care provider, etc.) and words associated with positive or negative stereotypes (weak/strong, sad/happy, shy/outgoing, etc.; Stern & Arenson, 1989) listed were evaluated to determine the degree to which participants identify as
these social identities. The responses were scored independently by two researchers. Each response was judged to be positive, negative, or neutral, and cancer-related or non-cancer-related (e.g., “fun” was scored as positive, non-cancer-related, and “survivor” was judged to be positive, cancer-related). The number of responses in each category were tallied and the two researchers’ ratings were averaged for each participant.

Statistical Analysis

Analysis was completed using SPSS version 21. The original analytic plan was to perform independent samples t-tests to check for differences between patient and partner in relationship satisfaction, emotional well-being and identity, a two-way analysis of variance to test for gender differences in emotional well-being among the two groups, and an analysis of covariance to test for differences in relationship satisfaction between the two groups based on perceived treatment intensity. However, due to the difficulty of recruiting participants and the small sample size there was not enough power to detect many of these differences, and since only one male respondent participated in the study, we were unable to test for gender differences between or within the groups.

Independent samples t-tests were run to check for between-group differences in relationship satisfaction, emotional well-being and identity. For the Who Am I? Test we conducted Cohen’s kappa test to measure inter-rater reliability. We also conducted Pearson correlations to see if any relationships existed between treatment intensity, emotional well-being, relationship satisfaction, and identity.
Results

**Relationship Satisfaction.**

Effect of relationship role on relationship satisfaction in AYA cancer patients and their partners was explored as a research question, since previous studies had shown that cancer can have detrimental or beneficial effects on the relationship functioning. While no significant differences were found in the overall score of relationship satisfaction or intimacy between groups, we did find that cancer patients and survivors ($M = 7.00, SD = 0.00$) experienced greater trust in their partner than did the romantic partners of cancer patients and survivors ($M = 5.80, SD = 0.96$), $t(4) = 2.79, p = .05, d = 1.77$.

**Emotional Well-being.**

We predicted that partner emotional well-being would be greater than patient emotional well-being; however, contrary to our hypothesis, we did not find any differences in emotional well-being between groups, as shown in Table 1. Specifically, there were no differences between patients and partners in dispositional optimism, positive affect, negative affect, or cancer-specific quality of life.

**Identity Status.**

Since no known previous studies had examined difference in identity with respect to relationship role in AYA couples facing cancer, the effect of relationship role on identity status was explored as a research question. In regard to relationship role, we found a marginally significant difference in identity status, with the romantic partners of cancer patients or survivors ($M = 1.00, SD = 0.00$) achieving higher
identity status than cancer patients and survivors ($M = 2.40, SD = 1.34$), $t(4) = -2.33, p = .08$, $d = 1.48$ (see Table 1).

The Who Am I test was scored independently by two researchers trained to rate each word as positive, negative, or neutral, and cancer-related or non-cancer-related. Cohen’s kappa test of inter-rater reliability showed low-moderate agreement, most likely due to the small number of cases; for cancer-related words $\kappa = .25, p = .08$, for non-cancer-related words, $\kappa = .30, p = .00$, for negative words, $\kappa = .78, p = .00$, for neutral words, $\kappa = .03, p = .726$, and for positive words, $\kappa = .07, p = .41$. To test for differences in number of responses to the Who Am I Test based on relationship role, ratings were averaged and then an independent samples t-test was performed. We found that the number of total responses and number of positive, negative, neutral, cancer-related or non-cancer-related responses did not differ based on whether the participant was a patient or partner.

**Treatment Intensity.**

Although it was not part of our hypothesis or research questions, we found, with regard to treatment intensity, that romantic partners ($M = 19.20, SD = 1.79$) rated the treatment to be more intense than the cancer patients and partners did ($M = 11.67, SD = 3.06$), $t(6) = -4.50, p < .001, d = 3.01$. 
Table 1

*Descriptive Statistics for Selected Measures by Patient and Partner Status*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Patient M (SD)</th>
<th>Partner M (SD)</th>
<th>t</th>
<th>df</th>
<th>p</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ego-Identity Status Overall</td>
<td>1.00 (0.00)</td>
<td>2.40 (1.34)</td>
<td>-2.33</td>
<td>4</td>
<td>.08</td>
<td>1.48</td>
</tr>
<tr>
<td>Overall Perceived Relationship Quality</td>
<td>113.67 (14.98)</td>
<td>102.20 (20.19)</td>
<td>.84</td>
<td>4</td>
<td>.43</td>
<td>.65</td>
</tr>
<tr>
<td>Perceived Relationship Quality: Intimacy</td>
<td>6.11 (1.02)</td>
<td>5.33 (1.55)</td>
<td>.77</td>
<td>4</td>
<td>.47</td>
<td>.59</td>
</tr>
<tr>
<td>Perceived Relationship Quality: Trust</td>
<td>7.00 (0.00)</td>
<td>5.80 (0.96)</td>
<td>2.79</td>
<td>4</td>
<td>.05</td>
<td>1.77</td>
</tr>
<tr>
<td>Life Threat and Treatment Intensity</td>
<td>11.67 (3.06)</td>
<td>19.20 (1.79)</td>
<td>-4.50</td>
<td>6</td>
<td>.00</td>
<td>3.00</td>
</tr>
<tr>
<td>Quality of Life- Cancer Survivors</td>
<td>5.47 (2.93)</td>
<td>4.70 (0.60)</td>
<td>0.53</td>
<td>6</td>
<td>.62</td>
<td>.36</td>
</tr>
<tr>
<td>Dispositional Optimism</td>
<td>9.67 (2.52)</td>
<td>12.60 (6.54)</td>
<td>0.72</td>
<td>6</td>
<td>.50</td>
<td>.59</td>
</tr>
<tr>
<td>Positive Affect</td>
<td>3.70 (1.04)</td>
<td>3.44 (1.20)</td>
<td>0.32</td>
<td>4.88</td>
<td>.76</td>
<td>.23</td>
</tr>
<tr>
<td>Negative Affect</td>
<td>2.10 (1.73)</td>
<td>3.12 (1.67)</td>
<td>-0.82</td>
<td>4.19</td>
<td>.46</td>
<td>.60</td>
</tr>
</tbody>
</table>

**Relationship Satisfaction and Treatment Intensity.**

We hypothesized that as treatment intensity increased, relationship satisfaction would decrease. We found this correlation with a moderate to large effect size to be in the hypothesized direction, but it was not significant $r (6) = -.42, p = .30$ (See Table 2; Cohen, 1988).
Table 2

*Bivariate Correlations*

<table>
<thead>
<tr>
<th></th>
<th>Life Threat and Treatment Intensity</th>
<th>Quality of Life-Cancer Survivors</th>
<th>Positive Affect</th>
<th>Negative Affect</th>
<th>Optimism</th>
<th>Overall Relationship Quality</th>
<th>Trust</th>
<th>Intimacy</th>
<th>Ego-Identity Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality Of Life-Cancer Survivors</td>
<td>-.40</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Affect</td>
<td>-.28</td>
<td>.71*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative Affect</td>
<td>.56</td>
<td>-.72*</td>
<td>-.27</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>.35</td>
<td>.10</td>
<td>.57</td>
<td>.57</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall Relationship Quality</td>
<td>.02</td>
<td>.26</td>
<td>.40</td>
<td>.23</td>
<td>.53</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td>-.42</td>
<td>.31</td>
<td>.57</td>
<td>-.04</td>
<td>.33</td>
<td>.82</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intimacy</td>
<td>.04</td>
<td>.31</td>
<td>.41</td>
<td>.16</td>
<td>.49</td>
<td>.99**</td>
<td>.82*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ego-Identity Status</td>
<td>.35</td>
<td>.16</td>
<td>.20</td>
<td>-.07</td>
<td>.29</td>
<td>-.40</td>
<td>-.45</td>
<td>-.37</td>
<td></td>
</tr>
<tr>
<td>Gender (1=male, 2=female)</td>
<td>-.33</td>
<td>-.34</td>
<td>-.55</td>
<td>-.55</td>
<td>-.95**</td>
<td>-.43</td>
<td>-.32</td>
<td>-.41</td>
<td>-.37</td>
</tr>
</tbody>
</table>

Note: ** p < 0.01, * p < 0.05
Discussion

The current study aimed to examine AYA romantic relationships where one partner had been diagnosed with cancer, a population that has been significantly under-researched in the past. AYA cancer patients and partners were evaluated with regard to three components of relationship functioning: relationship satisfaction, emotional well-being and identity. Due to the very small sample size of this study, there was not enough power to detect any existing small and moderate effect sizes of many of these differences. This research is very preliminary and further research is needed to determine if these constructs differ among the population of interest. Nonetheless, below the findings are discussed with reference to the broader literature.

Relationship Satisfaction

One of our research questions was whether there were differences in relationship satisfaction and intimacy ratings between cancer patients and partners. This was a previously untested question in the context of AYA cancer. We found there to be no significant difference between patients and partners in overall relationship satisfaction or intimacy. However, the findings from the current study suggest that trust, an important component of relationship satisfaction, differs in AYA cancer patients and survivors and their romantic partners. We found that cancer patients/survivors had more trust in their partner than did the romantic partners. This trust difference could be due to the fact that cancer patients are made more dependent on others as a result of their illness, and therefore must trust their partner to care for them (Zebrack & Isaacson, 2012). Also, partners may lose trust or dependability on their
partner due to their illness and treatment, which could cause lapses in memory, sometimes referred to as “chemo brain” or other possible issues such as their ill partner’s inability to work (Boykoff, Moieni, & Subramanian, 2009). This trust imbalance could also lead to communication issues that reduce relationship satisfaction (Manne, et al., 2010; Giese-Davis et al., 2000; Hannah et al., 1992). This finding suggests that it may be important for further research to consider how changes in trust impact the relationship, and work towards developing potential interventions that help build and maintain trust between the patient and partner throughout the cancer diagnosis and treatment.

**Emotional Well-being**

Contrary to our hypothesis that partner emotional well-being would be greater than patient emotional well-being, we did not find any differences in emotional well-being between groups. This could be due to having an inadequate sample size, or it could be because no difference actually exists in emotional well-being based on relationship role for AYA couples facing cancer. Since both couples are experiencing the same life-changing event, they may be equally as affected by the cancer diagnosis, which could explain the mixed results found in previous studies comparing patients’ and partners’ emotional well-being (Ben-Zur, 2001; Braun et al., 2007; Giese-Davis et al., 2000; Northouse, Templin, Mood & Oberst, 1998). Further research is needed to know for sure what is true for young adult cancer patients and their romantic partners.
Identity

Consistent with findings from previous research which found that AYA survivors of childhood cancer have a lower identity achievement level than healthy counterparts (Madan-Swain et al., 1999), this study found a marginally significant effect suggesting that AYA cancer patients may have lower identity achievement than others, in this case, partners of AYA cancer patients or survivors. This finding suggests that AYA cancer patients may need assistance in maintaining and defining their identity throughout their experience with cancer. It is important for mental healthcare professionals to understand how the cancer diagnosis affects each member of the relationship individually so that they know how to best help the couple throughout their cancer experience.

We did not find any significant differences in the amount of positive and negative or cancer-related and non-cancer-related words listed by cancer patients or partners in the Who Am I? Test. This could be explained by the fact that this is very preliminary research with quite a small sample size and the inter-rater reliability was low to moderate for this sample. However, we also may have found no difference because AYA patients and partners do not actually differ in the way the cancer diagnosis impacts their identity. Similar to what we found with emotional well-being, because both patient and partner are experiencing the life-changing cancer diagnosis, they may be equally as impacted by the experience. This construct needs to be evaluated by further research in order to explain exactly how a cancer diagnosis affects AYA romantic relationships.
Treatment Intensity

Another interesting finding of the current study was that AYA romantic partners viewed the treatment to be more intense than the patients and survivors, whom actually experienced the treatment, did. This could suggest that it is harder to watch someone you love go through something difficult than to actually experience it yourself, as these findings are similar to others that show that mothers rate their child’s treatment as more intense than the child (Stuber et al., 2007). As noted in previous research, treatment intensity can also be an important factor in relationship satisfaction for couples facing cancer together, with those receiving more intense treatments experiencing lower relationship satisfaction (Thompson, Marsland, Marshal & Tersak, 2009). If continued to be supported by further research, this suggests that it may be particularly important to focus on AYA couples facing more intense treatments in designing psychological interventions.

Gender differences

Although we expected to find that males would experience greater emotional well-being than females, regardless of the relationship role (Hagedoorn, Sanderman, Bolks, Tuinstra & Coyne, 2008), the very small sample of the current study prevented us from testing this effect. Additional research is needed to determine if this is true among AYA cancer patients and their partners.

Limitations, Strengths, and Future Directions

Limitations.

This study had many strengths in its research design, but it also faced many challenges. First and most obviously, was the sample size. The sample was too small
and did not have adequate power to detect differences between the groups. The biggest challenge faced in doing research on such a specific population is recruiting enough participants. Similar to others doing comparable research (Cantrell et al., 2012; Tercyak, Donze, Prahlad, Mosher, & Shad, 2006), the current study also struggled to get enough participation from adolescent and young adult cancer patients and their partners. Despite using a variety of web-based advertising and offering of incentives and raffle prizes for participating, recruitment was still a struggle. This could be due to many things. Unlike the previous successful studies on AYA relationships during cancer (Hannah et al., 1992; Carpentier et al., 2011; Thompson et al., 2009), this study was not associated in any way with a cancer treatment center, which would provide much easier accessibility the population of interest (Cantrell et al., 2012). Other studies that struggled to recruit AYA cancer patients for research noted that young adults are often simply too busy to find the time to participate in research or are lacking the awareness required for health-related studies (Tercyak et al., 2006).

Adolescence and young adulthood is also characterized by a lifestyle that makes it difficult to recruit them for research studies, as well as having less frequent contact with pediatric oncology departments where they may have received their treatment (Tercyak et al., 2006).

Another limitation of the current study is that cancer type was not limited to any certain diagnosis. The experiences from one form of cancer to another, including treatment type and severity of this illness, could vary greatly. Some forms of cancer, like breast, prostate, or testicular cancer can also have additional sexual complications
as opposed to other forms of cancer, like leukemia, which does not have direct sexual affects (Carpentier et al., 2011; Manne & Badr, 2008). However, it could also be argued that the fact that this study did not limit cancer diagnosis is indeed a strength. Because the study was open to all AYA cancer patients and partners regardless of the type of cancer with which they were diagnosed, the results provide a picture of what AYA cancer patients and partners experience more as a whole rather than trends specific to one cancer diagnosis.

**Strengths.**

Although the current study encountered problems with recruiting enough participants, there are many strengths to the research design. First of all, the study focused on an extremely under-researched population, AYA couples who had experienced a cancer diagnosis. There is extensive research on older adult romantic relationships during cancer, but very few studies have evaluated how young adult romantic relationships are affected by a cancer diagnosis. Additionally, this study tested both cancer patients/survivors and romantic partners of cancer patients/survivors and had them each complete the same survey so they could be directly compared. Many previous studies on AYA relationships focused their research on patients only (Carpentier et al., 2011; Thompson, Marsland, Marshal, & Tersak, 2009) and did not directly compare the two relationship roles as this study did. This research is important because it will help us understand how AYA relationships should be addressed within the cancer experience and what types of psychological interventions should be made. It will also help healthcare providers to determine how
to best acknowledge the role of the significant other and their important impact on the young cancer patient’s diagnosis and treatment.

**Directions for Future Research.**

In the future, it would be worthwhile to investigate these same constructs again with a large sample. Reaching the appropriate audience to get enough participation to detect the differences in relationship satisfaction, emotional well-being and identity will be a challenge, but it would be much easier if the study was conducted at a cancer clinic for teens and young adults. A larger sample will also allow researchers to test for gender differences in each relationship role and provide information on how relationships change with age, even within the AYA age group. It would also be advisable for future research to investigate the hypotheses in the current study longitudinally. Constructs such as identity formation are best measured over time, and the cross-sectional design of this study does not allow for monitoring the identity development of AYA cancer patients and their partners over time. Continued research is needed to figure out just how a cancer diagnosis affects AYA patients and partners individually, but also how it affects the functioning of their relationship.

**Conclusion**

Previous research provided mixed evidence for how we should expect cancer to affect young adult romantic relationships. Overall, this study found very preliminary evidence that AYA cancer patients achieve a lower level of identity, view their treatment as less severe, and have a higher degree of trust in their partner when compared to the romantic partners of AYA cancer patients. If replicated by further
research with a larger sample, this information could be used to help design and implement interventions to assist AYA couples through the difficulties they experience when one partner is diagnosed with cancer. This knowledge is important for healthcare providers so that they may know how to best help AYA patients and partners and the unique issues each faces as a result of the cancer diagnosis and treatment at that time in their lives.
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Appendix A

Pre-Consent Eligibility Criteria

Are at least 18 years of age? Yes or No

Do you reside in the United States? Yes or No

Are you a cancer patient or survivor? Yes or No

Are you the romantic partner or spouse of a cancer patient or survivor? Yes or No
Appendix B

Demographics

What is your:

Age? ___ years ___ months

Sex? Male Female

Race/Ethnicity? White, Black, Native American, Asian, Pacific Islander, Hispanic, Non-Hispanic

Highest level of education completed? Less than high school, high school/GED, some college, associate’s degree (2-year degree), bachelor’s degree (4-year degree), master’s degree, doctoral degree, professional degree

Marital status? Single, Dating, Engaged, Married, Divorced, Widowed

Sexual orientation? Heterosexual, Homosexual, Bisexual, Other

Length of relationship? ___ years ___ months
Appendix C

Cancer History

Patient or partner of patient? Patient or Partner

Your age at your/your partner’s diagnosis? ___years ___months

Month and year of cancer diagnosis? ______month, _____year

Type of cancer? _______________

Type of treatment(s)? Chemotherapy, Radiation, Surgery, Bone Marrow transplant, experimental, other(s)___________

Current treatment status? Not yet started treatment, currently in treatment, in remission, cured, choosing not to treat, other___________

Recurrence? Yes or No

Metastatic? Yes or No

Second Cancer diagnosis? Yes or No

Length of treatment? _____ years ____months

Treatment intensity? (Not very intense)1 2 3 4 5 6 7 8 9 10(exremely intense)