

Review article

Romantic and Sexual Relationships, Body Image, and Fertility in Adolescent and Young Adult Testicular Cancer Survivors: A Review of the Literature

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Abstract

This review presents a summary of existing knowledge regarding the effect of testicular cancer along four broad domains, including romantic and sexual relationships, body image, and fertility. A total of 37 studies were reviewed. Of note, most research consists of older adult testicular cancer survivors, with very little research attention afforded to adolescent and young adult survivorship. Relationship status (i.e., partnered versus unpartnered) appears to play an important role as it relates to adjustment outcomes in testicular cancer survivors. In addition, sexual function (and thereby fertility) and body image are also frequently compromised. Implications regarding a lack of developmentally focused research on adolescent and young adult testicular cancer survivorship are discussed, along with recommendations for new research. © 2010 Society for Adolescent Health and Medicine. All rights reserved.

Keywords:

Testicular cancer; Survivors; Adolescent and young adult; Relationships; Body image; Fertility

Testicular cancer is the most common solid-tumor cancer in adolescent and young adult (AYA) males aged 15–29 years. It accounts for 21.4% of cancers in this age group, which contrasts sharply with the prevalence of testicular cancer among 1–14-year-olds (2%) and 30–45-year-olds (7%) [1]. Despite its peak prevalence in the AYA years, testicular cancer is one of the most curable forms of cancer. Five-year survival rates range from 71% to 99%, depending on the extent of disease metastasis, with a mean overall 5-year survival rate of 95% [2]. Such high survival rates indicate that young men live a significant portion of their lives as testicular cancer survivors and, thus, remain at risk for a host of challenges associated with their testicular cancer history.

Relatively little research attention has been paid to AYA diagnosed with cancer of any kind. In fact, children (aged <15 years) with cancer have represented the focal point of most treatment and research, with dramatic advances made in these areas over the past several decades. This is despite

the fact that cancer is 2.7 times more likely to develop in individuals aged 15–29 years than in individuals younger than 15 years, and the incidence of cancer has increased more rapidly among AYA than among younger children [3]. Generally speaking, the relative improvement in survival rates among AYA has also failed to keep up with that achieved among childhood cancer patients, with recent trends suggesting a worse prognosis for AYA diagnosed with cancer today than 25 years ago [4].

Perhaps in no other form of cancer are the psychosocial challenges as clear as in testicular cancer, which occurs most commonly in the AYA years. Testicular cancer involves a male organ that is highly associated with perceptions of masculinity, attractiveness, sexual function, fertility, and romantic relationships—all critical aspects of AYA development [5–7]. The purpose of this article was to review the existing literature on the effect of testicular cancer on romantic and sexual relationships, body image, and fertility in adolescence and young adulthood. These topical areas were chosen because of their salience to the developmental period of adolescence and young adulthood [5,8,9]. Given the potential for testicular cancer to disrupt such important aspects of development along the AYA

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continuum, this particular form of cancer may represent a useful paradigm for developmental approaches to survivorship in other common AYA cancers.

Methods

PubMed, MEDLINE, and PsycINFO databases were used to identify published studies that met inclusion criteria for our literature review. The abstraction process was as follows: Articles containing the words “testicular cancer survivors” or “testis cancer survivors,” combined with phrases reflecting the population and constructs of interest (i.e., adolescents, teens, teenagers, young adults, relationships, sexuality, sexual function, body image, masculinity, attractiveness, or fertility) in the title, abstract, or keywords were requested. To ensure thoroughness, we repeated our searches using medical subject headings (MeSH) and also examined citations from previously located studies. Articles meeting the following criteria were selected for review: (1) published in English between 1980 and 2009, (2) study participants were in complete remission, and (3) an analysis of either qualitative or quantitative data regarding the effect of testicular cancer on romantic and sexual relationships, body image, or fertility. Previous literature reviews addressing similar topics in testicular cancer survivors were excluded after review of citations for original research publications. A total of 37 published studies met inclusion criteria and are summarized in Table 1.

Results

Romantic relationships

Only three studies [10–12] specifically assessed the topic of romantic relationships in testicular cancer survivors, albeit with largely older survivors (mean age, 32–35 years). No studies examined issues of romantic relationships among younger AYA testicular cancer survivors. Despite the lack of focused research on younger testicular cancer survivors, key themes are evident. Testicular cancer survivors who were in committed romantic relationships at the time of diagnosis describe improved physical and emotional adjustment to the cancer experience, often with increased closeness to their partner [10,12]. Similarly, men in a relationship throughout the diagnosis and treatment experience greater levels of social support, self-esteem, and overall mental health as compared with those who were unpartnered at the time of diagnosis [13].

Aside from the positive effects of being involved in a relationship at the time of testicular cancer, there is also evidence suggesting that, for a subgroup of survivors, testicular cancer exacerbates pre-existing relationship conflicts or creates new conflicts, at times leading to relationship dissolution [11,12,14]. For this subgroup of survivors experiencing relationship dissolution, cancer diagnosis and treatment lead to a greater appreciation of life in which pre-existing

relationship conflicts no longer have a place, thus leading survivors to end such conflict-plagued relationships. The cancer experience may also cause new conflicts which ultimately lead to relationship dissolution. For instance, 51.5% of survivors and 55.9% of survivors' spouses indicate special issues (e.g., financial concerns, fear of talking about cancer, possibility of recurrence, implications for the future) emerged after testicular cancer diagnosis and treatment. These were issues they felt could not be discussed with their spouse [15], suggesting that relationship problems centered on understanding and expressing emotional feelings with spouses also contribute to relationship dissolution among testicular cancer survivors [16].

Testicular cancer survivors unpartnered at the time of diagnosis express worry regarding how one's testicular cancer history may affect future interpersonal relations [10,12]. Unpartnered survivors report higher levels of cancer-related stress symptoms than do partnered survivors, suggesting that single survivors have fewer coping resources [17]. Being single at diagnosis appears to form a vulnerability that remains even when survivors develop a relationship after treatment completion. For instance, some survivors have noted that being a former testicular cancer patient caused difficulty throughout their marriage [18,19]. In addition, unpartnered testicular cancer survivors report worse satisfaction with erection and orgasm and lower overall sexual satisfaction as compared with partnered survivors, despite higher levels of sexual desire [19,20].

Sexual relationships

Relatively little data are available regarding the sexual relationships of general populations of young males, and particularly so among testicular cancer survivors. With this caveat in mind, an early study using qualitative interviews with 11 testicular cancer survivors in their early to mid-30s found that 18% of survivors were angered and/or saddened regarding changes in orgasm and the lack of normal ejaculation [10]. Results of a subsequent study [11] found that survivors were hopeful that the ejaculatory process would eventually return, but accepted sexual dysfunction as a necessary consequence of testicular cancer treatment. In contrast to the work of Brodsky [10,11], other research found few problems with impotence, loss of desire, sexual dissatisfaction, sexual frequency, and sexual communication [12]. Specifically, survivors reported that overall sexual interest, activity, enjoyment, and sexual function changed very little and, for many, not at all.

Among older survivors, studies of sexual function pre- and post-treatment found a moderate degree of survivor-reported sexual problems because of sexual satisfaction, sexual frequency, and erectile dysfunction [15,21–23]. Anxiety regarding sexual performance was more important during treatment as compared with pre-diagnosis, although anxiety diminished post-treatment [18]. Similarly, problems related to libido, erection, and ejaculation increased

Table 1
Published studies on romantic and sexual relationships, body image, and fertility in testicular cancer survivors

Study	N	Research question(s)	Methods	Findings
Arai et al. (1997)	85	To assess the effect of different treatment modalities on sexuality and fertility in TCS	Quantitative surveys	One-fourth to one-half reported some type of sexual impairment in each group (i.e., chemotherapy with RPLND, chemotherapy, radiotherapy, and surveillance). Approximately 70% of men with RPLND reported inability of ejaculation and a greater decline in semen volume. Rates and nature of sexual dysfunction of surveillance patients were similar to other treatment groups, except for ejaculatory function. About one-third reported feeling less attractive. Although 59% of the men in the chemotherapy group desired children, only 9% had fathered children since cancer treatment. In contrast, 44% of patients in the surveillance group have fathered children since their illness started.
Brodsky (1995)	11	To examine changes in self because of the experience of TC	Qualitative, open-ended interviews	Survivors partnered at diagnosis evidenced improved physical & emotional adjustment to cancer, while those unpartnered expressed worry regarding one's cancer history affecting future interpersonal relationships. Approximately 18% were angered/saddened regarding changes in orgasm and lack of normal ejaculation. More than half expressed concern with fertility, while others chose to purposefully ignore such issues. Many expressed regret that fertility was unnecessarily sacrificed due to a lack of knowledge regarding available fertility-preservation treatments.
Brodsky (1999)	11	To assess the experience of TC	Qualitative, open-ended interviews	Survivors' preexisting marital conflicts were exacerbated by the TC experience, leading to relationship dissolution. Survivors reported a greater life appreciation where preexisting conflicts no longer have a place. For those survivors experiencing sexual dysfunction, they were hopeful the ejaculatory process would eventually return, yet were resolved about the sacrificial nature of treatment. All survivors had been advised, and complied, with advice to bank sperm.
Brydoy et al. (2005)	1,433	To assess TCS' post-treatment paternity	Quantitative surveys	The paternity rate was high (71%), although many reported more difficulty with achieving paternity as compared to the general population. Mean time from diagnosis to birth of the first child was about 7 years, but varied according to treatment, with assistive reproductive technologies used by anywhere from 5% to 22% of couples who attempted conception after treatment completion.
Caffo & Amichetti (1999)	98	To explore sexual life in TCS	Quantitative surveys	Approximately 25% of TCS reported a low libido and 14% defined their sexual capacity as poor; 14% of TCS avoided sexual contact after treatment because of the disease and/or its therapies. In addition, 14% reported premature ejaculation, 2% late ejaculation, and 2% absence of ejaculation. Most TCS considered the information provided by their physician about the sexual sequelae of therapy to be insufficient.
Carroll et al. (1987)	22	To assess fertility in men with TC on a surveillance protocol	Laboratory analysis	About 45% of men had abnormal spermatogenesis on the basis of low sperm count or sperm motility. Of these men, 50% recovered normal spermatogenesis when re-evaluated 4–19 months later. Avoidance of RPLND seemed to spare fertility in at least a small percentage of these patients.

(Continued)

Table 1
Published studies on romantic and sexual relationships, body image, and fertility in testicular cancer survivors (*Continued*)

Study	N	Research question(s)	Methods	Findings
Chapple & McPherson (2004)	45	To understand reasons for and against seeking prosthesis	Qualitative, open-ended interviews	Reasons for opting for a prosthesis included fear of loss of masculinity, concern about self image, a desire to look normal, and a desire to feel whole again. Reasons against seeking prosthesis included thinking the loss of a testicle was not visibly obvious, lack of impact on self image, not a long-term threat to masculinity, living with one testicle was comfortable, no desire for additional surgery, and concern about safety issues.
Dahl et al. (2007)	1,084	To explore sexual function in TCS	Quantitative surveys	TCS had significantly worse scores on ejaculatory and sexual problems in both young (20–39 years) and middle-aged (40–59 years) groups. Overall sexual problems were expressed by 38.8% of TCS vs. 35.5% in the normative population. Overall sexual problems were associated with increasing age, lack of a partner, and a higher anxiety score, while ejaculation problems were associated with lack of a partner and a trend for chemotherapy and neurotoxic side effects.
Drasga et al. (1983)	28	To explore fertility after chemotherapy in TCS	Retrospective chart review	Normal sperm counts were found in 46% of TCS; only 17% were azoospermic. A total of 32% of TCS had impregnated their wives, resulting in 5 healthy babies, 1 spontaneous abortion, and 3 ongoing pregnancies
Fleer et al. (2006)	350	To assess cancer-related stress symptoms in TCS	Quantitative surveys followed by qualitative, open-ended interviews with a subsample of 30	Thirteen percent of TCS reported cancer-related stress symptoms, with single survivors, those with less education, and those unemployed reporting higher levels of stress. Perceptions about the impact of cancer on current life and fear of the future were factors in the presence or absence of cancer-related stress symptoms.
Foster et al. (1993)	53	To preliminarily assess fertility in TCS who underwent RPLND	Quantitative surveys and laboratory analysis	Approximately 81% of TCS treated with nerve-sparing RPLND reported success in fathering children. Semen analyses and DNA histograms suggested fertility in >70% of TCS.
Foster et al. (1994)	201	To assess fertility in TCS who underwent RPLND	Quantitative surveys and laboratory analysis	Of those TCS who attempted pregnancy after nerve-sparing RPLND, 76% were successful. Results of semen analysis also found 75% of TCS to be in the normal range.
Girasole et al. (2006)	129	To assess frequency of sperm banking and characterize differences between men choosing to bank sperm or not	Quantitative surveys	Overall, 24% of survivors had banked sperm. Men who banked sperm were, on average, 10 years younger and less likely to have children at the time of diagnosis. The use of banked sperm was low (<10%), and many men could have children without using banked sperm
Gritz et al. (1989)	88	To assess psychosocial sequelae in TCS and their wives or partners	Combined qualitative interviews and quantitative surveys	TCS experienced significant depletion of energy, increased fear of cancer, interference with sleep and cognitive function, and sexual difficulties during and after treatment. The moderate degree of survivor-reported sexual problems was due to problems with sexual satisfaction, sexual frequency, and erectile dysfunction.
Hannah et al. (1992)	58	To compare marital and sexual functioning of TCS and Hodgkin's survivors and their spouses	Combined qualitative interviews and quantitative surveys	Approximately 51.5% of TCS and 55.9% of TCS' spouses indicated special issues (i.e., financial concerns, fear of talking about cancer, possibility of recurrence, future implications) had emerged after diagnosis and treatment and these were issues they felt could not be discussed with their spouse. A substantial proportion of TCS disclosed negative changes in body image and sexual frequency. Among TCS' spouses, 88.2% reported no decrease in their perceptions of their partners' attractiveness, while 32.4% reported a reduction in sexual frequency

(Continued)

Table 1
Published studies on romantic and sexual relationships, body image, and fertility in testicular cancer survivors (*Continued*)

Study	N	Research question(s)	Methods	Findings
Hartmann et al. (1999)	98	To examine types and incidences of sexual dysfunction and fertility distress in TCS	Quantitative surveys	TCS who were treated with RPLND alone or secondary resection of residual retroperitoneal tumor mass (SRRTM) reported higher incidence of sexual dysfunction, namely ejaculation problems. TCS who received both RPLND and SRRTM reported a more frequent unfulfilled wish for children. Reasons for reduced fertility included azoospermia, erectile dysfunction caused by psychosocial distress, and permanent dry ejaculation. Overall, sexual dysfunction and infertility affected approximately 20% of TCS.
Herr et al. (1998)	105	To assess long-term paternity in men with TC initially managed by surveillance	Combined qualitative interviews and quantitative surveys	About 46% of TCS fathered children while on active surveillance whereas 19% fathered children after treatment for relapse. Of the couples who attempted pregnancy on surveillance, 65% were successful
Huddart et al. (2005)	680	To examine fertility and sexual function in TCS	Quantitative surveys	In total, 30% of TCS reported attempting conception of whom 77% were successful and a further 10 TCS were successful after infertility treatment, with an overall fertility rate of 82%. Reduced fertility was associated with previous chemotherapy treatment and elevated FSH levels. Overall sexual function was satisfactory, although there was a tendency for treated groups, as opposed to the surveillance group, to have less sexual activity and less sexual interest. Radiotherapy treatment was also associated with reduced sexual enjoyment.
Incrocci et al. (2002)	123	To assess treatment outcome, body image, and changes in sexuality after TC	Quantitative surveys	About 20% of TCS reported less interest and pleasure in sex and less sexual activity, while 17% had erectile difficulties. Cancer treatment had negatively influenced sexual life in 32% of TCS. Approximately 52% found that their body had changed after treatment.
Joly et al. (2002)	190	To assess QOL and social problems in TCS	Quantitative surveys	Health-related QOL scores did not differ significantly between TCS and healthy controls, nor did general symptom scores. Psychosocial problems were reported equally by TCS and controls. TCS reported more modification of sexual life, due mainly to decreased sexual enjoyment, decreased sexual desire, and infertility, as compared to healthy controls.
Jonker-Pool et al. (2004)	314	To assess the need for information and support in TCS versus lymphoma survivors	Quantitative surveys	More than half of TCS reported a lack of information and support concerning sexuality, at diagnosis and follow-up, while rates for patients with malignant lymphoma were lower. TCS who suffered sexual dysfunction reported extremely high needs for information and support.
Lange et al. (1983)	34	To assess the impact of RPLND and chemotherapy on fertility in TCS	Quantitative surveys and laboratory analysis	In TCS who underwent RPLND, 42% experienced spontaneous return of ejaculation. Both patients who reported trying to father a child succeeded. About 75% of TCS treated with chemotherapy experienced some return to normal spermatogenesis 18 months or more post-treatment, as evidenced by normal FSH levels and/or the presence of live sperm in the ejaculate
Levison (1986)	46	To evaluate the impact of post-operative radio-and chemotherapy in TCS	Quantitative surveys	TCS reported no change in either libido or potency, although post-operative treatment caused sterility in 37% of TCS previously known to be fertile
Narayan et al. (1982)	55	To assess ejaculation and fertility after RPLND in TCS	Laboratory analysis	Antegrade ejaculation had returned spontaneously in 45% of TCS. Five TCS had fathered children post-operatively. Antegrade ejaculation was induced with sympathomimetic drugs in 5 patients, 1 of whom fathered a child while taking the drugs.

(Continued)

Table 1
Published studies on romantic and sexual relationships, body image, and fertility in testicular cancer survivors (*Continued*)

Study	N	Research question(s)	Methods	Findings
Ozen et al. (1998)	140	To assess sexual and professional performance of TCS	Quantitative surveys	TCS reported that problems related to libido, erection, and ejaculation increased significantly during treatment and subsequently recovered but did not return to baseline following treatment. Unpartnered TCS reported thinking that their cancer history would be a concern for a future partner. Regarding professional lives, 22.4% of TCS thought they had better performance after treatment compared to before treatment, whereas 6.1% reported it to be worse.
Rudberg et al. (2000)	277	To assess health-related QOL in TCS	Quantitative surveys	Health-related QOL of TCS was as good or even better than that of men in the general population. Men treated with chemotherapy, either alone or in tandem with other treatments, scored less favorably on QOL. Perceived attractiveness, being fertile, having children, and living with a partner were the most important aspects of good health-related quality of life.
Rudberg et al. (2002)	669	To compare frequency of physical and psychologic symptoms in TCS as compared to general population controls	Quantitative surveys	Approximately 14% of TCS reported deteriorated sexual functioning, with these men reporting significantly more distress symptoms during the last month. Men treated with radiation therapy plus chemotherapy and/or RPLND scored lower in sexual interest and the ability to enjoy sex; they also reported more erectile difficulties. Regarding attractiveness, 15.2% reported that they felt less attractive as compared to before treatment. Men who reported decreased attractiveness experienced more symptoms than those who found themselves equally or more attractive than before treatment; they also reported lower scores on sexual functioning. TCS who perceived themselves as attractive as before had fathered children more often than those assessing themselves as more attractive or less attractive than before treatment.
Schover & von Eschenbach (1985)	121	To assess sexual and marital relationships in TCS	Quantitative surveys	Compared with healthy men, TCS reported less sexual activity, lower sexual desire, more erectile dysfunction, more difficulty achieving orgasm, reduced orgasmic intensity, and for 82%, greatly reduced semen volume. Erectile and orgasmic problems were more prevalent when radiotherapy was used and, the longer the time since treatment, the more likely TCS were to have antegrade ejaculation. About 13% of TCS were divorced/separated, and those whose marriages ended cited sexual dysfunction and cancer treatment as a significant source of marital stress.
Sheppard and Wylie (2001)	27	To assess sexual difficulties in TCS	Quantitative surveys followed by qualitative, open-ended interviews with a subsample of 7	A common theme was the perceived support of being in a committed relationship which TCS believed helped them adjust physically and emotionally to having cancer and treatment. Evidence of sexual dysfunction included few problems with impotence, loss of desire, sexual dissatisfaction, sexual frequency, and sexual communication. Body image concerns also emerged, including feeling self-conscious and anxious about whether others notice the missing testicle, as well as feeling different to others.
Spermon et al. (2003)	226	To assess prevalence of fertility/infertility in men before and after TC	Quantitative surveys	Before TC, 66% of couples who attempted to conceive succeeded within 1 year. After treatment, 43% of couples who attempted to conceive succeeded within 1 year. Seven couples utilized banked sperm to conceive a child after treatment.

(Continued)

Table 1
Published studies on romantic and sexual relationships, body image, and fertility in testicular cancer survivors (*Continued*)

Study	N	Research question(s)	Methods	Findings
Tamburini et al. (1989)	31	To assess impact of TC on partner relationship and sexual function	Quantitative surveys	A small subsample of TCS reported worsening of the emotional relationship with their partner following treatment. Sexual dysfunction was low overall, with most dysfunction associated with loss of ejaculation following RPLND. Anxiety scores among those TCS with reported sexual dysfunction were low, however
Tinkler et al. (1992)	276	To assess sexual function among TCS treated with radiotherapy as compared to surveillance and normal controls	Quantitative surveys	A significant difference emerged between TCS treated with radiotherapy and controls in erection, ejaculation, and libido, with the treated group performing less well. A deterioration in sexual function was observed with increasing age. Almost 24% of radiotherapy TCS felt disabled or disfigured by the treatment, most commonly due to the presence of only one testicle.
Tuinman et al. (2005)	259	To compare marital and sexual satisfaction of TCS and their spouses to a reference group, and to compare marital and sexual satisfaction of couples partnered during TC to couples partnered after TC	Quantitative surveys	Survivors and spouses of both couple groups reported similar marital satisfaction as couples of the reference group. Survivors and spouses of couples during TC and survivors of couples after TC reported less sexual satisfaction than the reference groups. Survivors of couples after TC reported less sexual satisfaction than survivors of couples during TC.
Tuinman et al. (2006)	129	To explore self-esteem, social support, and mental health in TCS, on the basis of relationship status	Quantitative surveys	Social support was equal across groups, although satisfaction with support was not. Survivors with a relationship during TC were most satisfied with support and had the highest self-esteem and mental health. Survivors with a relationship after TC reported next best functioning but had the same mental health as singles. Singles and survivors with a relationship after TC had lower mental health than a reference group of men. The difference in self-esteem between singles and survivors with a relationship during TC appeared most distinct.
Tuinman et al. (2010)	93	To assess sexual functioning during the first year after TC and examine the effect of relationship status and depressive symptoms on sexual functioning	Quantitative surveys	Orgasmic functioning, overall satisfaction, and total sexual functioning decreased between T1 (after orchiectomy) and T2 (3 months later) and increased to a level above T1 at T3 (12 months later). Levels of erectile functioning and sexual satisfaction were higher at T3 than at T1 and T2, although desire remained stable. Singles reported worse sexual functioning at all time points than partnered survivors. Depressive symptoms had small to moderate predictive power on sexual functioning at T2, but not at T3.
Turek et al. (2004)	149	To assess safety and effectiveness of a new saline-filled testicular prosthesis	Quantitative surveys	Subjective assessment of testicular appearance was significantly improved, yielding significant increases in body esteem and general self-esteem 1 year post-implant, as well as a significant increase in self-comfort during sexual activity. Prostheses were also found to be safe and well-tolerated.
Wiechno et al. (2007)	326	To assess the degree of the degree of hormonal abnormalities in TCS and the effect of these changes on TCS' QOL	Quantitative surveys	Anxiety rate was 27%–28% while the depression rate was 15%–18%. About 40% of TCS had erectile dysfunction, with men with abnormal estradiol more prone to erectile dysfunction. Higher depression levels were found among patients with elevated LH or FSH. Elevated gonadotropins correlated with deteriorations in physical well-being.

Note: DNA = deoxyribonucleic acid; LH = luteinizing hormone; FSH = follicle stimulating hormone; QOL = quality of life; RPLND = retroperitoneal lymph node dissection; SRRTM = secondary resection of retroperitoneal tumor mass; TC = testicular cancer; TCS = testicular cancer survivors.

significantly during treatment, and functioning did not appear to fully return to baseline after treatment completion [24,25]. Contemporary neurophysiologic models of male sexual function suggest a central nervous system sexual inhibition during periods of high stress [26]. Post-treatment anxiety and depression is common (10%–20% of survivors) and may be associated with abnormal levels of gonadotrophins [27]. Type of cancer treatment has clear implications for sexual function, with a higher incidence of problems observed in survivors who underwent retroperitoneal lymph node dissection (RPLND) alone or a secondary resection after chemotherapy, as compared with those treated with chemotherapy alone [16,28].

Other research has compared sexual relationships of testicular cancer survivors with those of healthy controls. Survivors report more modification of sexual life, mainly because of decreased sexual enjoyment and sexual desire as compared with healthy controls [14,29–32]. Survivors also report more ejaculatory dysfunction and erectile dysfunction than controls: up to 40% report erectile dysfunction 2 or more years post-treatment [27]. Sexual problems appear to cut across age lines, with more problems noted in both younger (20–39 years) and middle-aged (40–59 years) groups, compared with healthy controls [33]. Characteristics associated with sexual problems in survivors include increased age, lack of a partner, higher overall anxiety, lower testosterone, being treated with radiation therapy plus chemotherapy and/or RPLND, and longer time since treatment [14,16,31–34]. Notably, a majority of survivors report a need for information regarding sexuality, particularly those survivors with evidence of sexual dysfunction [23,35]. Sexual dysfunctions among adolescents aged <20 years have not been examined.

Body image

As with romantic and sexual relationships, little research has examined body image among testicular cancer survivors, with the work in this area focused on older (mean age, 32–35 years) survivors. None of the research has assessed body image issues across the span of younger AYA testicular cancer survivors. Earlier work with 11 older survivors suggested survivor indifference toward orchiectomy, irrespective of whether prosthesis was chosen or not [10]. Participants reported feeling no less masculine, and perceived orchiectomy as acceptable if loss of a testicle did not hinder sexual relationships. Survivors' concerns related only to scars receiving unwanted attention. Such results differ from more recent research indicating that 16% of survivors experience significant body image concerns [12]. Specifically, survivors describe feeling self-conscious and anxious about whether others notice the missing testicle, as well as feeling different from others.

Other studies of primarily older samples of testicular cancer survivors consistently demonstrate effects on body image. Arai et al [24] and Hannah et al [15] found that approximately one-third of survivors reported a decrease in overall attractiveness, whereas Rudberg et al [31] found that 15.2%

of survivors reported feeling less attractive. Although 52% of survivors endorsed feeling that their bodies had changed significantly since cancer and treatment [30], interestingly, 88.2% of survivors' spouses reported no decrease in their partners' attractiveness [15]. Body image is an important aspect of choice regarding a testicular prosthesis, with reasons centered around fear of loss of masculinity, concern about self-image, and the desire to look "normal" and to "feel whole again" [32,36]. Follow-up evaluation of testicular prostheses (in a sample that included a significant number of adolescents) shows significant increases in both body esteem and general self-esteem (1 year post-implant), as well as significant increase in self-comfort during sexual activity (assessed among adults only) [37].

Very little research has focused on identifying covariates of body image changes among survivors, although recent work suggests that testicular cancer survivors with low testosterone feel less masculine as compared with survivors with normal testosterone levels [34]. Although unstudied, these issues may be especially relevant for early and middle adolescent males who are experiencing, or have recently experienced, the physical changes of puberty that lead to a newly organized sense of sexual self [9]. For instance, gynecomastia is a relatively common, normal occurrence in male puberty. However, a maximum of 11% of patients with testicular cancer have gynecomastia at the time of initial presentation, and approximately 4% of males evaluated for gynecomastia have an associated testicular cancer [38]. Gynecomastia may persist after testicular cancer treatment, especially in the presence of relatively common post-treatment imbalances of testosterone and estradiol [27]. On the basis of the data from older men, it is reasonable to assume that testicular cancer in younger adolescents will adversely affect an emerging sexual identity and subsequent romantic and sexual relationships.

Fertility

As is the case with romantic and sexual relationships and body image research, fertility has largely been examined among older testicular cancer survivors. Concern with post-treatment fertility is an issue for more than half of some samples of testicular cancer survivors [10]. A few survivors purposefully choose to ignore issues related to potential post-treatment fertility, citing inappropriate timing for starting a family as a primary reason. Many participants report regret that fertility may have been unnecessarily sacrificed because of a lack of knowledge regarding available fertility-preservation treatments. However, results of a subsequent study of testicular cancer survivors suggest progress in this area, with all participants being advised, and complying with advice, to bank sperm [11].

A relatively larger literature exists regarding fertility issues in older samples of testicular cancer survivors. Reduced fertility is related to decreased quality of life among testicular cancer survivors [16]. Reasons for reduced fertility include

azoospermia, erectile dysfunction caused by psychosocial distress, and permanent dry ejaculation [28,39]. Although a majority of survivors father children, many report more difficulty after treatment completion as compared with the general population or individuals in surveillance [24,29,34,40,41]. Mean time from diagnosis to the birth of the first child post-treatment is about 7 years, but varies according to treatment, with assistive reproductive technologies used by approximately 5%–22% of couples who attempt conception after treatment [34,40]. Semen quality after orchiectomy depends on the cell type of the tumor, with lower average sperm counts ($8.0 \times 10^6/\text{mL}$) among men with nonseminomatous cancers compared with those with seminomatous cancers (mean = $23.99 \times 10^6/\text{mL}$) [42]. Survivors treated with chemotherapy and secondary resection of residual retroperitoneal tumor mass report an unfulfilled wish for children more often, as compared with survivors treated with chemotherapy-only, surveillance, or primary RPLND [28,43–48]. Only 24% of testicular cancer survivors choose sperm cryopreservation before treatment; interestingly, men choosing cryopreservation, on average, are 10 years younger and less likely to have children at the time of diagnosis as compared with men declining cryopreservation [49]. Only a small minority of survivors (<10%) actually make use of the stored sperm.

Summary

Several key findings are evident based on our current review of the literature, although such findings must be interpreted in light of the fact that the available data may be skewed by length of time since diagnosis from when the data were collected. As some of the older cohorts may have been further out from treatment, their reports are clearly contingent upon the natural history of adjustment to testicular cancer and its treatment. With these limitations in mind, data clearly emphasize that the presence or absence of a romantic partner at the time of testicular cancer diagnosis is critically important in determining adjustment outcomes. Among testicular cancer survivors who were partnered at the time of diagnosis, partners play a critical role in helping them adjust to the cancer experience and providing much needed support, although there is also some evidence that suggests that cancer may pose an initial or ongoing strain on relationships. Testicular cancer survivors who are faced with navigating the cancer experience without a romantic partner have unique issues of their own, the major being their worry regarding how disclosure of their cancer history may effect future romantic relationships. Despite these apparent differences based on partner status, it is important to also consider the possibility that simply being partnered does not make testicular cancer survivors resilient to the negative effects of cancer and its treatment, but rather, partnered survivors may be systematically different from unpartnered survivors.

With regard to sexual relationships and body image in testicular cancer survivors, the literature is equivocal. Some

work with survivors in their early to mid-30s suggests the presence of sexual dysfunction with regard to orgasm and ejaculation, whereas other work has found that sexual function changed insignificantly after diagnosis and treatment of testicular cancer. Similarly, some research has failed to find any significant body image issues, whereas other research has found that a significant proportion of testicular cancer survivors do indeed evidence significant concerns with their bodies. A comparatively larger body of work with older samples of testicular cancer survivors suggests, however, the presence of significant sexual and body image issues. Specifically, testicular cancer survivors experience decreased libido and sexual satisfaction, as well as increased ejaculatory and erectile dysfunction as compared with healthy controls. More invasive treatment, such as RPLND or secondary resection after chemotherapy, is associated with higher incidence of sexual dysfunction. Moreover, testicular cancer survivors consistently report fear of loss of masculinity, a desire to look “normal,” and a desire to “feel whole again.”

A small but relatively consistent body of research addresses fertility issues of testicular cancer survivors. Qualitative studies suggest that more than half of the survivors experience infertility and worry about infertility. Many survivors also worry that fertility may have been sacrificed unnecessarily. In particular, survivors feel that insufficient information was received regarding potential fertility preservation treatments. Although many testicular cancer survivors are able to conceive after treatment completion, the process can be prolonged.

Implications

On the basis of findings regarding the effect of testicular cancer during adolescence and young adulthood, several implications are suggested. First, research devoted specifically to examination of testicular cancer in adolescents and young adults is relatively rare. Most existing research does not address the potential interactions of testicular cancer and its treatments with the developmental tasks of adolescence and young adulthood (i.e., identity exploration, establishment of close intimate relationships). Testicular cancer affects a male organ that is highly associated with masculinity, attractiveness, sexual function, fertility, and romantic relationships—all key aspects of adolescence and young adulthood. For this reason, additional research focus is warranted specific to AYA testicular cancer survivors.

Second, the current literature review highlights the fact that being unpartnered at the time of diagnosis is associated with greater worry about future disclosure of cancer history, cancer-related stress symptoms, and sexual dysfunction. Such data call attention to the importance of social support that may be of particular importance for unpartnered adolescents. Even after survivors have developed a relationship, it is imperative to continue monitoring that relationship, as well as related constructs such as general mood, social support, and quality of life, given that being single at diagnosis

appears to form a vulnerability that remains even when survivors develop a relationship post-treatment. Importantly, monitoring and support of survivors should be extended to partners in tandem with survivors themselves so as to ensure optimal relational and individual functioning. Finally, for individuals who are partnered at diagnosis, simply being partnered does not appear to be sufficient for positive adjustment; thus, similar monitoring of outcomes throughout survivorship is recommended.

Third, sexual function (and thereby fertility) and body image have also often been compromised through treatment and thereby represent additional targets for continued research. In particular, additional qualitative research is needed that explores, in survivors' own words, the effect of testicular cancer on such domains. The gathering of such data will allow for identification of survivor needs and the subsequent development and testing of interventions that address such needs.

Research Recommendations

As is quite evident through the current review of the literature, research specific to AYA testicular cancer survivors is lacking. However, simply conducting additional research in this area is insufficient in understanding the unique issues specific to a testicular cancer diagnosis in adolescence or young adulthood. Many events occur throughout the AYA years that set the stage for the successful transition into adult life, and a diagnosis of testicular cancer can threaten the timing and/or nature of such events.

Individuals report a first girlfriend or boyfriend by ages 12–13, a first kiss by age 13, a first date by ages 14–15, and first “being in love” by age 16 [9]. As early as 10–12 years, individuals also report increasing sexual interest, which is followed by romantic objectification at ages 12–14, and romantic or sexual focus by age 15. Other key events in the adolescent years involve gender identity, sexual responsiveness, and capacity for close dyadic relationships [8]. As individuals enter adolescence, an emerging sexual identity may additionally be refined as the physical changes of puberty produce questions such as “How much like a ‘normal’ male am I going to be?” or “How sexually attractive am I going to be?” The newly organized sense of sexual identity has important implications for sexual responsiveness, thus influencing how close dyadic relationships (both sexual and nonsexual) are formed and experienced in adolescence. During this time, romance is typically “recreational,” occurring more often in groups rather than dyads, with short-lasting relationships that may or may not involve sexual experiences. However, as adolescents transition into young adulthood, they begin to explore their identities in a number of arenas, particularly in love and romantic relationships. During this time, love is more intimate and serious, lasts longer, occurs mostly at the dyadic rather than group level, typically involves a sexual relationship, and may also involve cohabitation, marriage, and parenthood [5].

Given the timing and nature of socio-emotional and psychosexual development that occurs in the AYA years, AYA testicular cancer survivorship research should be couched within a developmental framework that recognizes the importance of romantic and sexual relationships. To illustrate, a young man who is diagnosed with testicular cancer at 15 years of age is in a very different developmental stage than a young man who is diagnosed at the age of 25. The 15-year-old is living at home with parents, has only recently become interested in romantic or sexual partners, and likely has given no thought at all to having children or telling a future romantic partner about his testicular cancer diagnosis. On the contrary, a 25-year-old is likely physically and financially independent from his parents, involved in a potentially serious relationship, and has begun to think about getting married or starting a family someday in the near future (if not already). Clearly, the developmental tasks at hand of the 15- and 25-year-old differ markedly, as do the mechanisms involved in each patient's adjustment, both during and after treatment for testicular cancer.

By adopting a developmental framework, the nature of the questions we ask AYA testicular cancer survivors and how we ask such questions become incredibly important. In our review of the literature, it appears that existing research has a heterosexual bias that assumes all testicular cancer survivors are heterosexual men and that they are inevitably monogamous. These assumptions may reflect biases or gaps in the literature to date—rather than the full range of lifestyles and realities for those men affected—and suggest that attention is needed regarding the role of testicular cancer in same-sex relationships. Similarly, recruiting AYA testicular cancer survivors at all stages along the continuum (i.e., early, middle, and late adolescents to young adults), and follow-up of survivors over time and through various stages of development is critically important to informing a more complete understanding of the effect of testicular cancer on adolescence and young adulthood. Careful documentation of these trajectories is also imperative in designing interventions that can be administered at key points along the survivorship continuum to best effect positive outcomes for this particularly vulnerable population of survivors. Importantly, and as was noted earlier, AYA cancer patients and survivors in general are overlooked and under-researched. It is anticipated that the current focus on testicular cancer can provide a useful paradigm for developmental approaches to survivorship in other common AYA cancers. Moreover, testicular cancer may also represent a useful paradigm for examining relational and sexual outcomes that have yet to be explored in other conditions involving the testes, such as testicular torsion or congenital solitary testis.

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