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Quality of life in long-term cervical cancer survivors

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Abstract

Objectives. To describe the quality of life (QOL) and long-term psychosocial sequelae of women of childbearing age diagnosed with cervical cancer 5–10 years earlier.

Methods. Utilizing a cross-sectional descriptive design, 51 cervical cancer survivors and 50 age-matched controls completed a comprehensive QOL interview.

Results. Participants were predominantly married, non-Hispanic White, with a mean age at diagnosis of 37 years and a mean age at interview of 45 years. This disease-free sample enjoys a good QOL, with physical, social, and emotional functioning comparable to or better than comparative norms. However, certain psychological survivorship sequelae and reproductive concerns persist. Participants reporting good QOL were less likely to report ongoing coping efforts related to having had this illness and were more likely to report greater social support, greater sexual pleasure, and less cervical cancer-specific distress. In a multiple-regression model, cancer-specific distress, spiritual well-being, maladaptive coping, and reproductive concerns accounted for 72% of the variance in QOL scores. Fifty-nine percent of respondents expressed that they would likely participate in a counseling program today to discuss psychosocial issues raised by having had cervical cancer, and 69% stated that they would have attended a support group program during the initial treatment if it had been offered.

Conclusions. This information provides insight into the complex survivorship relationships between QOL and sequelae of cervical cancer for women diagnosed during childbearing years. Therefore, it is important for health care professionals to recognize that aspects of cancer survivorship continue to require attention and possible follow-up care.
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Keywords: Long-term cervical cancer survivorship; Quality of life; Sexual dysfunction; Reproductive concerns

Introduction

Cervical cancer continues to be an important health problem, with an estimated 12,200 new cases expected for 2003 in the United States [1]. Due to improved screening rates, the majority of cases are now diagnosed in earlier stages, resulting in longer disease-free intervals and improved survival rates as compared to one decade ago [2–4]. With the improved screening efforts and better treatment regimens, there is a greater opportunity and necessity to examine long-term quality of life (QOL) and survivorship characteristics in this population of women.

A substantial body of literature supports the need to examine QOL among cervical cancer survivors. While numerous short-term physical, psychological, social, and sexual disruptions have been noted [5–13], few studies have described the long-term impact of cervical cancer on QOL. Furthermore, a sizeable proportion of cervical cancer cases are diagnosed at a relatively young age, yet little is known about long-term adjustment and survivorship in this population. Some literature indicates that adverse physical and psychosocial effects may be serious and persistent among younger women diagnosed with cancer [14,15]. Long-term QOL can be affected in several ways in this vulnerable group. The anatomical changes resulting from the cancer or its treatment may permanently impair sexual function and reproductive ability and significantly impact self-image and social well-being [9,16]. The psychological and spiritual toll can be severe as survivors recognize the importance of both continued surveillance and possible recurrent cervical cancer [8,11,12,16,17].

To our knowledge, long-term (i.e., 5> years) cervical cancer survivors have not been studied previously. The purpose of this paper is to describe the QOL of childbearing age women diagnosed with cervical cancer 5–10 years earlier, and to identify factors that may compromise or enhance QOL.

Materials and methods

Study design and recruitment

In this case-control study, case eligibility included women diagnosed with cervical cancer 5–10 years earlier and were between the ages of 17 and 45 at the time of diagnosis and without recurrence or a second malignancy. Controls were matched to cases on age and race, and were ineligible if they had reported having a hysterectomy. Women diagnosed with Gestational Trophoblastic Disease (GTD) or Lymphoma (Hodgkin's and non-Hodgkin's) were also enrolled in this study. This paper provides data on the cervical cancer cohort only. Women were identified from two cancer registries: (1) the Cancer Surveillance Program of Orange County (CSPOC) at University of California, Irvine (UCI) and (2) the Colorado Central Cancer Registry (CCCR). Eligible patients received a letter of invitation describing the study and a telephone call 1–2 weeks later to answer questions and request participation. After written informed consent was obtained, research assistants administered the study questionnaire during a 45-min telephone interview. Alternatively, eligible women could complete a mailed, written version of the questionnaire. Upon completing the questionnaire, the participant was asked to provide the name, address, and telephone number of three female acquaintances of the same race/ethnicity within 5 years of the participant's age, not blood relatives and without a personal history of cancer. These women were then contacted and invited to join the study as control subjects. The Institutional Review Board at AMC Medical Center and UCI approved the study.

Participants

Cases

Of 179 women identified for this study through the CSPOC Cancer Registry at UCI, 22 completed the questionnaire and provided signed informed consent, 1 completed the questionnaire and provided verbal consent only, 4 were deceased, 4 were ineligible, 7 declined, 103 were unable to be contacted due to confirmed wrong addresses and phone numbers, and 38 did not respond to the mailed packet and follow-up phone calls. Of 75 survivors identified through the Colorado Cancer Registry, 29 completed the questionnaire, 4 refused, 16 did not respond, and 26 were unable to be contacted. In summary, 254 cervical cancer survivors were identified at both registries; of these, 191 women could not be contacted or were found to be ineligible for this study. Sixty-three eligible women were successfully contacted and invited to participate; 51 survivors (81%) completed the questionnaire.

Controls

Fifty unaffected acquaintance controls completed the questionnaire: 15 cervix controls, 21 lymphoma controls, and 14 GTD controls. The cervix and lymphoma controls were enrolled at AMC and UCI; the GTD controls were enrolled in Boston. Although we were unable to match at least one control per case, the ascertained controls provide valuable information, especially regarding measures that have not been normed on the general population (i.e., Reproductive Concerns Scale, Gynecologic Problems Checklist). While the original design was to have matched cases and controls, this approach did not yield the expected results. Thus, all controls are used and considered as an unmatched design.

Measures

The questionnaire included sociodemographic characteristics, medical and cancer history, and instruments that assessed the following variables of interest:

(1) *Quality of life*. General health QOL and cancer-specific QOL were assessed in both cases and controls. (a) The Medical Outcomes Study Short Form 36-item health survey (SF-36) [18] measured general QOL. This measure is widely used to compare study samples with the general population, containing eight individual scales that are part of the three general areas of health-related QOL [19,20]. The eight subscales assess physical functioning, role limitations due to physical problems, bodily pain, general health, vitality, social functioning, role limitations due to

emotional problems, and mental health. Internal consistency for cases ranged from 0.84 to 0.93 for the eight subscales and for the controls ranged from 0.69 to 0.91. The SF-36 can also be scored as two summary scales—the Physical (PCS) and Mental Component Summary scales (MCS) [21]. The total population has a mean score of 50, and a score of 60 or 40 represents one standard deviation (SD) above or below the mean, respectively. Higher scores indicate better functioning for each subscale. Ninety-nine percent of adults in the general population score from 17 to 64 on the PCS, and from 16 to 63 on the MCS [21]. (b) Cancer-*specific QOL* was measured in the survivor group by the Quality of Life-Cancer Survivorship (QOL-CS) scale [22]. This instrument includes 46 items representing four QOL domains: physical, psychological, social, and spiritual well-being. The psychometric properties of this scale were established from responses of a heterogeneous cancer survivor population. Authors report overall test–retest reliability of 0.89. In this study, the overall internal consistency was excellent (r = 0.93) (subscale alphas ranged from 0.59 to 0.93). Ten items specific to cancer survivorship were clustered to form a survivor-specific distress subscale (Cronbach's alpha = 0.88). These items, which we refer to as survivor-specific distress, include feelings of distress associated with diagnosis and treatment, as well as fear of a future cancer.

(2) *Psychological distress* was measured in the survivor group with the Impact of Event Scale (IES), [23] a well-validated, 15-item Likert scale to measure psychological distress related to cancer. The two IES subscales examine intrusive thoughts and feelings, and avoidance of thoughts and feelings related to the stressful situation. In this study, the IES has good internal consistency (Cronbach's alpha = 0.91 for the intrusive scale, 0.81 for the avoidance scale, and 0.91 for the total scale).

(3) *Sexual functioning* was measured in both cases and controls in two formats: (a) The Gynecologic Problems Checklist (GPC), which was developed for this study to identify the type and magnitude of gynecologic problems. Two subscales emerged from this checklist: gynecologic problems (e.g., pelvic pain, vaginal dryness) (Cronbach's alpha = 0.72) and sexual dysfunction (e.g., pain with intercourse, loss of interest in sexual activities) (Cronbach's alpha = 0.90). (b) The Sexual Activity Questionnaire (SAQ) [24] assessed aspects of sexual function potentially influenced by hormonal status: desire, frequency, satisfaction, vaginal dryness, and penetration [24]. Although the scale was constructed for use in the Tamoxifen Prevention Trial [25] wherein 85% of the women had a strong family history of breast cancer (age range 35–65), this measure may yield important

findings for women surviving gynecologic malignancies. In this study, the two subscales had acceptable internal consistency: discomfort subscale (Cronbach's alpha = 0.74), and pleasure subscale (Cronbach's alpha = 0.82).

(4) *Reproductive concerns* in both cases and controls were measured with an 18-item Likert scale constructed for this study to assess cognitive and affective factors associated with infertility and reproductive concerns. Sample questions were "I feel less of a woman because of reproductive problems", "I am less satisfied with my life because of reproductive problems", "I am content with the number of children that I have". In this study, an excellent Cronbach's alpha was observed (0.90). Further analyses suggest that criterion-related and construct validity were also respectable.

(5) *Social support* in cases and controls was measured by the Interpersonal Support Evaluation List (ISEL), a well-validated self-report measure of perception of instrumental and emotional support [26] using true–false statements. In this study, Cronbach's alpha was 0.69.

(6) *Spiritual well-being* was measured in cases and controls by the Functional Assessment of Cancer Therapy-Spirituality Scale (FACT-Sp), a 12-item scale examining spiritual beliefs [27]. This scale measures various aspects of spirituality, such as a sense of meaning in one's life, harmony, peacefulness, and a sense of strength and comfort from one's faith. The FACT-Sp has high internal consistency (Cronbach's alpha = 0.87) [27]. In this study, Cronbach's alpha was 0.69.

(7) *Coping efforts* were measured in the survivor group by the 24-item Coping Orientations to Problems Experienced (COPE) scale [28]. The COPE is a self-report, Likert-style questionnaire, which asks people to indicate to what extent they use a variety of strategies to cope with a particular stressful event (in this case, a prior cervical cancer diagnosis). Twelve subscales represent adaptive coping methods (i.e., active coping, emotional support, positive reframing, planning, humor, acceptance, religion, venting) and less adaptive methods (i.e., distraction, denial, substance abuse, behavioral disengagement). In this study, Cronbach's alpha for the adaptive subscale was 0.93 and 0.78 for the maladaptive coping scale.

Data analysis

Data were analyzed with SAS for Windows, Version 8.2 (Statistical Analysis System, 1999). Descriptive statistics were generated to characterize the study sample in terms of sociodemographic, medical, and QOL parameters. Frequencies, means, medians, standard deviations, and ranges for each measure were established and compared to normative

data, when available. Comparisons of demographic and psychosocial data were conducted using the *t* test for continuous variables, Likelihood Ratio Chi-Square test for unordered categorical variables, and Fisher Exact test for dichotomous variables. The Bonferroni test, which controls for experiment-wise error, was used to perform multiple comparisons between the three control groups (i.e., cervical, lymphoma, and GTD control groups). Univariate analysis (Pearson product moment correlations) was used to determine the relationships between age, psychosocial, gynecologic, and reproductive variables. To account for the multivariate relation of the predictor variables to QOL, a stepwise multiple regression was performed. Cancer specific-distress was the first variable added to the model. Then, patient age, social support, spiritual well-being, coping, reproductive concerns, and gynecologic functioning were added as a second set to the model. The alpha level was set at $P \leq 0.05$ to determine statistical significance.

Results

Demographic and health variables

The majority of cervical cancer participants were married, non-Hispanic white, and college-educated, with a mean age at diagnosis of 37 years (range 25–45) and a mean age at the time of the interview of 45 years (range 31–55). The average time between the year of diagnosis and year of interview was 8.0 years (range: 4–11 years). The majority reported a total household income of $35,000 or more (Table 1). By self-report, cervical cancer treatments included surgery only (63%); surgery and radiation (16%); surgery, radiation, and chemotherapy (12%); surgery and chemotherapy (2%); radiation (4%); and unsure (3%). Of the 47 survivors who received surgery (92% of the total), 81% received a radical hysterectomy, and 19% received a hysterectomy and oophorectomy.

The unaffected acquaintance controls matching to cervical cancer, GTD, and lymphoma cases were compared on several factors (i.e., age, social support, physical and mental functioning, sexual discomfort and pleasure scores). Although the cervix controls reported more gynecological pain symptoms than the GTD controls ($P < 0.05$), they were not statistically different from each other on any other variable. Thus, the three control groups were collapsed into one group. Finally, we compared the controls and cases to determine if they were demographically comparable. Cervical cases were older than controls at the time of interview, with the greatest proportion clustered in the 41–55 age group ($P = 0.0021$); mean age at interview for controls was 41 years (range 28–54). Additionally, there was a larger percentage of minorities within the cervical cases (9.8% versus 2%) ($P = 0.10$), and cases age 45 and younger were less likely to be married at the time of the interview compared to the younger controls (31% versus 56%) ($P =$

Table 1
Sociodemographic characteristics of cervical cancer survivors and controls

Characteristic	Cervical cancer cases (N = 51)		Controls (N = 50)	
	Mean (SD)	N (%)	Mean (SD)	N (%)
Age at diagnosis (years)	37.1 (5.3)		–	
Age at interview (years)[a]	45.0 (5.3)		41.3 (6.5)	
Time since diagnosis (years)	8.0 (1.8)		–	
Race/Ethnicity				
Non-Hispanic white		46 (90.2)		49 (98.0)
Hispanic		4 (7.8)		1 (2.0)
Other		1 (2.0)		
Marital status at interview				
Married		31 (60.8)		39 (78.0)
Not married		20 (39.2)		11 (22.0)
Education				
High school grad <		13 (23.5)		10 (20.0)
Some college or >		38 (76.5)		40 (80.0)
Employment status				
Employed		39 (76.5)		36 (73.5)
Unemployed/retired		12 (23.5)		13 (26.5)

[a] $P = 0.0021$.

0.06). The controls were similar to cases on all other sociodemographic variables.

General quality of life

As noted in Table 2, cervical cancer survivors reported good QOL, as measured by the SF-36. The physical (PCS) and mental component (MCS) means were comparable to normative means, with a mean PCS of 53.0 (SE = 1.34) and MCS of 48.4 (SE = 1.64), and were not statistically different from the study control means where PCS = 53.2 ($P = 0.92$) and MCS = 51.2 ($P = 0.22$). The majority of SF-36 physical and mental component scores were distributed around the mean and ± 1SD. Better physical status was significantly associated with less cancer-specific distress ($P < 0.05$) and less maladaptive coping ($P < 0.05$). Better mental status was associated with less cancer-specific distress ($P < 0.01$), better social support ($P < 0.0001$), better spiritual well-being ($P < 0.0001$), better sexual functioning ($P < 0.01$), and fewer reproductive concerns ($P < 0.01$).

Cancer-specific quality of life

As indicated in Table 2, cervical cancer survivors generally reported good QOL, particularly evident in the social and physical well-being domains. The QOL survivor-specific subscale indicates that approximately half of the participants were fearful of future diagnostic tests and a

Table 2
Means and standard deviation of QOL measures[a]

QOL dimension	Scale	Cervical cancer cases Mean (SD)	Controls Mean (SD)	Normative data	P value[b]
General QOL[c]	SF-36				
	Physical component score	53.0 (9.6)	53.2 (8.6)	50.0 (10.0)	0.57
	Mental component score	48.4 (11.7)	51.2 (11.0)	50.0 (10.0)	0.08
Cancer-specific QOL[d]	QOL-CS				
	Overall well-being	7.0 (1.7)	–	6.51 (1.31)	–
	Survivor-specific distress	5.5 (2.3)	–	–	–
Sexual functioning[e]	SAQ[f]				
	Discomfort	4.2 (1.9)	5.1 (1.2)	–	0.0125
	Pleasure	13.7 (4.5)	13.7 (2.7)	–	0.94
Gynecologic symptoms[g]	GPC				
	Gynecologic problems	10.2 (4.8)	8.1 (1.9)	–	0.0068
	Sexual dysfunction[f]	8.7 (4.6)	7.5 (2.6)	–	0.16
Reproductive concerns[h]	RCS	34.1 (14.9)	21.7 (3.7)	–	<0.0001

[a] $N = 51$ cervical cancer cases and $N = 50$ controls, unless otherwise specified. Normative data provided if available.
[b] Analysis of covariance test between cases and controls, controlling for age at interview.
[c] Higher score indicates better functioning (possible range: PCS 2–76 and MCS 0–81).
[d] Higher score indicates better well-being (possible range 0–10).
[e] Higher score indicates better sexual functioning (possible range Discomfort 0–6, Pleasure 0–18).
[f] $N = 35$ cervical cancer cases and $N = 40$ controls.
[g] Higher score indicates more gynecologic symptoms (possible range Problems 6–30, Dysfunction 5–25).
[h] Higher score indicates more reproductive concerns (possible range 18–90).

recurrent or second cancer. They also reported disease-related concerns, which persisted despite remaining disease free. Several important predictors of distress during survivorship emerged: survivor-specific distress was significantly associated with younger age ($P < 0.01$), less social support ($P < 0.001$), more reproductive concerns ($P < 0.001$), worse mental status ($P < 0.0001$), and lower spiritual well-being scores ($P < 0.01$).

Cancer-specific distress, efforts to cope, and social support

A sizeable proportion of cases attributed current distress to their cancer: 39% thought about their cancer sometimes or often in the past week when they did not mean to, 27% reported that other things made them think about the cancer, 26% tried to avoid getting upset when they thought about the cancer, 25% said that any reminder brought back feelings about the cancer, and 20% still had waves of strong feelings about the cancer. It is noteworthy that cancer-specific distress was associated with several global areas of psychosocial functioning: those with poorer social support reported significantly greater distress ($P < 0.01$), and were more likely to report current efforts to actively cope with the disease by using maladaptive coping methods (i.e., denial, substance abuse) ($P < 0.0001$). There were no differences between cases and controls in perceived social support.

Sexual functioning

Of the 51 cervical cancer survivors interviewed, 16 (31%) were not sexually active at the time of the interview.

They cited several reasons for no sexual activity (participants may cite multiple reasons): no partner (44%), not interested and/or had a partner who was not interested (38%), fatigue (13%), physical problems (13%), and other reasons (50%). Of the 50 control participants, 10 (20%) were not sexually active, due to: no partner (60%), fatigue (10%), partner too tired (10%), partner not interested (10%), partner had a physical problem (20%), and other reasons (20%). Sixty-six percent of cases and 12% of controls were taking Hormone Therapy (HT) at the time of interview. Although a majority of survivors and a minority of controls were taking HT at the time of interview, survivors still reported significantly more sexual discomfort, as measured by the SAQ (Table 2) than controls, even after controlling for age at interview ($P < 0.02$). In addition, Table 3 illustrates that survivors reported significantly more experiences of hot flashes ($P < 0.02$) and vaginal dryness than controls ($P < 0.02$). Survivors also reported significantly more pain with penetration ($P < 0.03$). Although there was no significant difference in sexual pleasure between the two study groups, an item-by-item comparison on several indicators of sexual dysfunction (Table 3) suggest a trend in which cervical cancer survivors report more sexual problems overall than controls (e.g., pain with intercourse, problems having an orgasm). Univariate analysis indicates that cases who reported sexual functioning problems also reported poorer QOL ($P < 0.01$).

Reproductive concerns

When compared to healthy controls, cervical cancer survivors reported significantly more reproductive concerns

Table 3
Gynecologic problems checklist

% Reporting problem somewhat to very much during past month	Cx cases (N = 51)	Controls (N = 50)	P value[a]
Gynecologic problems			
Hot flashes/flushes	31.4%	12.0%	0.0166
Pelvic pain	13.7%	8.0%	0.35
Vaginal dryness	38.0%	16.3%	0.0143
Vaginal bleeding	0.0%	4.0%	0.09
Vaginal infection	12.0%	4.0%	0.13
Vaginal/vulvar irritation	13.7%	4.0%	0.08
	Cx cases (N = 35)	Controls (N = 40)	
Sexual dysfunction[b]			
Lost interest in sexual activities	28.6%	22.5%	0.55
Problems feeling sexually aroused	31.4%	17.5%	0.16
Problems having an orgasm	22.9%	12.5%	0.24
Pain with intercourse	20.0%	10.0%	0.22
Difficulty having Intercourse due to cancer Tx	5.9%	n/a	–

Cx = Cervical cancer; Tx = treatment; n/a = not applicable.
[a] Chi-Square for overall difference in proportion of cases and controls reporting somewhat to very much of a problem.
[b] Based on participants reporting current sexual activity.

($P < 0.0001$) (Table 2). Descriptive data suggest that reproductive concerns are related to sadness about inability to bear children (31%), inability to talk openly about fertility (30%), frustration related to childbearing inability (25%), and mourning the loss of ability to have children (25%). Reproductive concerns for survivors were associated with poorer QOL ($P < 0.0001$), more cancer-specific distress ($P < 0.01$), less social support ($P < 0.01$), lower spiritual well-being scores ($P < 0.05$), greater gynecologic pain ($P < 0.0001$), and poorer sexual functioning ($P < 0.05$).

Predictors of quality of life

The resulting model of QOL outcomes suggests that spiritual well-being, maladaptive coping, and reproductive concerns will predict individual differences in QOL, even when cancer-specific distress is taken into account (Table 4). These four predictors accounted for 72% of the variance in QOL scores of the sample. Post hoc analysis was done to test for multi-collinearity among variables and demonstrated that each of the predictors had unique effects on QOL [29].

Desire for counseling

Cervical cancer survivors indicated that at diagnosis, 69% would have desired counseling. Additionally, 59% indicated that they would currently attend counseling to address survivorship concerns. In general, survivorship concerns were related to long-term treatment side effects (e.g., hormones, gastrointestinal and abdominal problems, weight problems), recurrence and mortality concerns, and psychosocial concerns.

Discussion

The majority of cervical cancer QOL investigations have focused on the acute and re-entry phases of survivorship. This study characterizes QOL issues of younger, long-term female cervical cancer survivors, thereby contributing to the literature a description of a group of women who have previously been unstudied within the survivor population. Although on standardized measures of general health and well-being cervical cancer survivors compare favorably to healthy controls, "pockets of disturbance" [8] persist for this group of cancer survivors in subtle, but important areas reflecting an adjustment to life after cancer.

As anticipated, sexual functioning appears compromised due to physical discomfort, with cervical cancer survivors reporting significantly more discomfort than controls even after controlling for age. Cancer survivors reported a greater incidence of hot flashes and vaginal dryness. Further, trends in the proportional differences of gynecologic symptoms strongly suggest that cervical cancer survivors continue to struggle with problems which could negatively affect sexual functioning and gynecologic health. Since this sample size for this exploratory study was relatively small, these additional proportional differences were not statistically significant due to insufficient power. However, the clinical significance of these data is important, given the implications for follow-up gynecologic care for this population. Future sexual functioning studies could further elucidate problems by comparing those who have had a hysterectomy due to cancer versus a benign problem with those who have not had this surgery.

Consistent with other cancer survivorship literature [14], younger aged survivors appear to experience greater distress. In this study, women who evidenced greater survivor-specific distress also reported less social support, less confidence managing their illness, more reproductive concerns, worse general health, and lower spiritual well-being. It is necessary to further examine the contribution that each of these variables make in predicting who is more likely to experience persistent vulnerabilities associated with survivorship. For example, these data suggest that survivors who report less social support are more likely to utilize multiple coping strategies to manage illness-related stressors. One might speculate that those with less social support and other psychosocial limitations attempt to compensate

Table 4
Predictors of overall quality of life scores among cervical cancer survivors (N = 49)

Variable	B	F	P
Cancer distress	−0.03	6.45	0.0147
Spiritual WB	0.07	18.11	0.0001
Maladaptive coping	−0.14	4.88	0.0325
Reproductive concerns	−0.03	11.09	0.0018

Overall F value: 31.89, $P < 0.0001$. Adjusted R^2: 0.72.

through continued active coping. While this can be considered adaptive, those cured of disease 5–10 years earlier should theoretically have little objective evidence of illness. Therefore, it is important for health care professionals to recognize that aspects of cancer survivorship continue to require attention and possible follow-up care.

This study was an initial effort to identify how cervical cancer diagnosed during childbearing years might be associated with other life domains. Particularly among cervical cancer survivors, little hope for future fertility has traditionally been offered. This vulnerability could affect functioning in subtle, unforeseen ways. Our data suggest that those with the greatest unresolved reproductive issues may have associated long-term physical and psychosocial disruptions. Although no cause-and-effect relationship can be inferred, it is reasonable to hypothesize that cervical cancer survivors who experience significant negative effects due to compromised childbearing may be at risk for long-term diminished QOL (e.g., gynecologic pain, poorer health and well-being, less social support). In this regard, it is also tempting to speculate that the trend in marital status differences between cases and controls is related to the cancer. In our sample of 39 cases married when diagnosed, the majority (28) remained married at the time of the interview. Four of the 9 participants who divorced or separated after cancer indicated that this change was related to their cancer. Although small in number, the proportion who attributed their divorce to cervical cancer is sizeable, suggesting an area for further exploration given the stress that this disease might place on the relationship.

This study has several limitations which restrict generalizability. First, despite our recruitment efforts through cancer registries, the almost exclusively Caucasian cervical cancer survivor sample is not generally representative of women with this disease. A more strategic approach is necessary in future research to recruit minority and medically underserved cervical cancer survivors, who share a greater proportion of the disease burden but continue to be underrepresented in survivorship studies. Second, although we intended to enroll age- and race-matched acquaintance controls, cases were hesitant to provide names and contact information of acquaintances. Given the amount of time that elapsed from the cancer diagnosis to the point of interview (i.e., 5–10 years), and the hesitance to provide contact information, it is difficult to know what, if anything, controls knew regarding the previous cancer diagnosis of the cases. Although trends in the data suggest that cervical cases are more likely to cluster in the lowest QOL quartiles compared to controls, overall comparisons should be viewed with caution, particularly given that the general QOL scores of cases and controls QOL were comparable to age-matched normative data.

A better understanding of long-term QOL in cervical cancer survivors of childbearing age can help health care providers inform patients about possible long-term limitations. This could be an important consideration for clinical care, since well-informed cancer patients are often likely to do better in managing disease sequelae [30]. Although these data are retrospective, it is significant that the majority of the cervical cancer survivors surveyed desired counseling related to cancer-specific issues. This information should be important to clinicians as treatment and follow-up planning unfold. Likewise, long-term QOL data can inform investigators to design prospective trials and tailor interventions at an earlier phase in the survivorship trajectory.

Acknowledgment

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