

Do ongoing lifestyle disruptions differ across cancer types after the conclusion of cancer treatment?

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Abstract

Introduction Cancer interferes with participation in valued lifestyle activities (*illness intrusiveness*) throughout post-treatment survivorship. We investigated whether illness intrusiveness differs across life domains among survivors with diverse cancers. Intrusiveness should be highest in activities requiring physical/cognitive functioning (instrumental domain). Intrusiveness into relationship/sexual

functioning (intimacy domain) should be higher in prostate, breast, and gastrointestinal cancers than in others.

Methods Cancer outpatients ($N=656$; 51% men) completed the Illness Intrusiveness Ratings Scale (IIRS) during follow-up. We compared IIRS Instrumental, Intimacy, and Relationships and Personal Development [RPD] subscale and total scores across gastrointestinal, lung, lymphoma, head and neck, prostate (men), and breast cancers (women), comparing men and women separately.

Results Instrumental subscale scores ($M_{\text{men}}=3.05$ – 3.80 , $M_{\text{women}}=3.02$ – 3.63) were highest for all groups, except prostate cancer. Men with prostate cancer scored higher on Intimacy ($M=3.40$) than Instrumental ($M=2.48$) or RPD ($M=1.59$), p 's < .05; their Intimacy scores did not differ from men with gastrointestinal or lung cancer. Women collectively showed higher Instrumental ($M=3.39$) than Intimacy ($M=2.49$) or RPD scores ($M=2.27$), p 's < .001, but not the hypothesized group difference in Intimacy.

Conclusions Post-treatment survivors continue to experience some long-term interference with activities requiring physical and cognitive functioning. Sexual adjustment may be of special concern to men when treatments involve genitourinary functioning.

Implications for Cancer Survivors Ongoing monitoring with the IIRS to detect lifestyle interference throughout survivorship may enhance quality of life. Screening and intervention should target particular life domains rather than global interference.

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Keywords Cancer diagnosis · Cancer survivorship · Illness intrusiveness · Psychosocial factors · Quality of life

After cancer treatment has been completed successfully, many survivors report ongoing limitations that compromise

their sense of well-being [1–3]. Research concerning health-related quality of life during cancer survivorship largely focuses on short- and long-term biomedical outcomes (e.g., fatigue, pain, sleep disorders, neurocognitive changes, and symptom burden) [3–8], but these introduce additional stress to the extent that they render it more difficult for cancer survivors to remain actively involved in the activities and pursuits that give purpose and meaning to life, a phenomenon we termed *illness intrusiveness* [9].

The central premise of the illness intrusiveness theoretical framework (Fig. 1) theorizes that disease and treatment factors (e.g., lingering side effects) interfere with the capacity to continue engaging in valued activities (e.g., work; recreation; familial, couple, and social relationships), thereby reducing subjective well-being and inducing emotional distress [10]. Illness intrusiveness likely reflects a powerful determinant of subjective well-being following cancer treatment: survivors report ongoing challenges in regaining pre-morbid employment and financial status [11–13], social life [13, 14], family and other relationships [8, 11, 15], and sex life [13, 16–18]. These normal spheres of activity are essential to personal and social identity and to self-esteem, including during and after the cancer experience [19, 20]. When people encounter difficulties in resuming such activities, they experience distress as well as other negative psychological consequences, such as feeling as if one is a burden on others, stigma, compromised self-concept, reduced self-esteem [13, 21–23], disappointment with treatment outcomes because of limitations [23], and poorer overall quality of life [24, 25].

Studies of illness intrusiveness in cancer have mostly examined illness intrusiveness globally [21, 26, 27]. Because cancer is a heterogeneous category of diseases, however, difficulties in re-engaging in activities may vary depending on the affected anatomical site and/or treatment effects. People with different types of cancer and those who receive different cancer treatments may report similar intensities of emotional distress, but the factors responsible

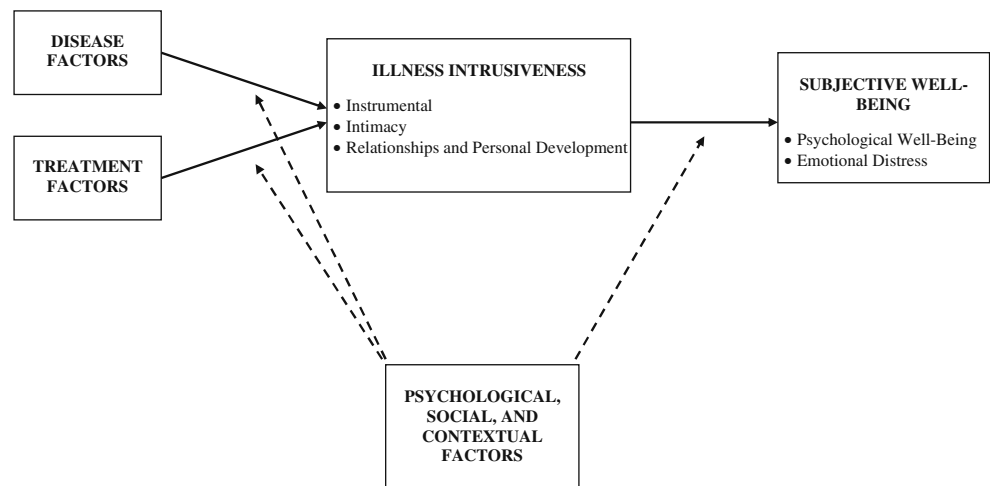
for the experienced level of stress may differ as a function of the biomedical consequences specific to their disease and treatment. By identifying distinct lifestyle domains (e.g., types of activities) that are differentially vulnerable to such disruptions, it may be possible to characterize particular cancers or treatments in terms of their associated illness-intrusiveness disruptions.

Cancer and cancer treatments have yet to be compared in terms of their impact on illness intrusiveness into distinct life domains. Cancer survivors often report long-term declines in physical functioning [8, 28]. Thus, for most cancers, the overriding impact of illness intrusiveness likely involves activities that require intact physical and cognitive functioning, such as work and active recreation [12, 29, 30].

Some cancers and their treatments involve sites with direct physiological or psychological associations to sexuality and may, therefore, greatly affect sexual functioning and couple adjustment. In men with prostate cancer [18, 31–33] or certain gastrointestinal cancers [13, 34, 35], treatments can produce erectile and/or ejaculatory dysfunction due to pelvic-nerve damage, which, in turn, impacts satisfaction with sex life, relationship adjustment, and sexual self-image. Hence, difficulties with sexual and couple functioning are likely more salient to men with these cancer types than to men with cancers that do not affect genitourinary functioning. Similarly, sexual and couple functioning can be affected in women with breast [16, 36, 37] and gastrointestinal cancers [13, 34], although not as consistently as in men with prostate cancer [38–40]. Women with breast and gastrointestinal cancers may report greater interference with sexual and couple functioning than women with cancers that do not impinge so directly on sexuality.

The current study compares illness intrusiveness across different domains of activity among survivors of gastrointestinal, head and neck, lymphoma, lung, prostate (men only), and breast (women only) cancer. We conducted the comparisons separately in men and women because the

Fig. 1 The central premise of the illness intrusiveness theoretical framework. Disease and treatment effects interfere with the capacity to engage in valued activities and interests (illness intrusiveness), which, in turn, adversely affects subjective well-being. The Illness Intrusiveness Ratings Scale Illness measures intrusiveness into three life domains—Instrumental, Intimacy, and Relationships and Personal Development



sexes respond differently depending on whether the affected life domain is central to their roles (e.g., work for men, relationships and nurturance for women) [41, 42]. We employed the *Illness Intrusiveness Ratings Scale (IIRS)* [9], a self-report instrument that measures illness-induced interference with three general domains of life experience: (a) *Instrumental*—work, active recreation, financial situation, and health; (b) *Intimacy*—relationship with one's spouse and sex life; and (c) *Relationships and Personal Development*—family relations, other social relations, self-expression, religious expression, community/civic involvements, and passive recreation [43].

We hypothesized that (1) most survivors would report the highest illness intrusiveness on the Instrumental subscale (i.e., activities requiring physical and cognitive functioning); (2) men with prostate and gastrointestinal cancers would report greater intrusiveness on the Intimacy subscale (i.e., sexual and couple functioning) than men with cancers that do not affect sexual functioning directly (head and neck, lymphoma, and lung cancers); and, correspondingly, (3) women with breast and gastrointestinal cancers would report greater Intimacy-related intrusiveness than women whose cancers do not affect sexual functioning directly.

Methods

Participants

Between July 2000 and July 2001, we recruited a sample of cancer patients who had completed active treatment and were attending outpatient clinics at Princess Margaret Hospital, a comprehensive cancer center in Toronto, for a study concerning satisfaction with the physician-patient interaction [44]. The study afforded the opportunity for a secondary analysis of reported illness intrusiveness in men and women with cancer. Equal numbers of women and men across six common cancer diagnoses were sampled: gastrointestinal, head and neck, lymphoma, lung, prostate (men only), and breast cancer (women only). Inclusion criteria included fluency in English and attendance at the clinic for post-treatment follow-up. Research assistants approached patients about the study as they awaited routine follow-up appointments with their oncologists.

A total of 699 participants (349 men, 350 women) completed the questionnaires. Unfortunately, response rate was not documented. We restricted analyses to data from respondents who provided responses for at least 75% of the items within each IIRS subscale, to reduce the impact of missing data. The final sample for analysis comprised 656 respondents (335 men, 321 women; 93.8% of the initial

participants); of these 656 respondents, 95% of the men and 98% of the women had no missing data. We imputed missing data by prorating. As compared to the final sample, the 43 excluded respondents were more likely to be female (67.4% vs. 48.9%), $\chi^2(1, N=699)=5.53, p=.02$. They were less likely to be married (37.2% vs. 72.8%), $\chi^2(4, N=697)=42.66, p<.001$, or working for pay (22.0% vs. 44.2%), $\chi^2(5, N=693)=11.64, p=.04$. Included and excluded respondents did not differ in educational level, diagnosis, or tumor severity.

Table 1 summarizes the final sample's sociodemographic and medical characteristics. Most participants were married, had achieved high school to college education, and approximately half were still working for pay. Approximately half had no evidence of disease. Most had been diagnosed 3–6 years earlier. Significant differences were observed across cancer types in age, occupation, time since diagnosis, and tumor status. These variables were thus controlled statistically in all analyses.

Materials

The questionnaire package included the *Illness Intrusiveness Ratings Scale (IIRS)* [9], a 13-item self-report instrument in which respondents rate the extent to which "illness and/or its treatment" interfere with each of 13 life domains central to quality of life, using a 7-point rating scale (1 = "Not Very Much", 7 = "Very Much"). A total score is calculated as the sum of all 13 item ratings. The IIRS has demonstrated strong psychometric properties across diverse chronic-disease [45–47] and cancer groups [17, 21, 26, 30] (see [48] for review). The IIRS generates three subscales that include 12 of the 13 items: *Instrumental* (work, financial situation, active recreation, and health items), *Intimacy* (relationship with spouse and sex life items), and *Relationships and Personal Development* (family relations, other social relationships, self-expression, religious expression, community/civic involvements, and passive recreation items) [43, 49]. The diet item did not represent one subscale uniquely [43] and so is excluded. Subscale scores consist of the mean ratings of the items included in a subscale. Higher scores thus indicate greater illness intrusiveness (i.e., more extensive interference with activities).

Sociodemographic and medical information was documented for descriptive and statistical-control purposes, using a self-report questionnaire developed for this study.

Procedure

The hospital's Research Ethics Board approved the study. A research assistant approached people with cancer while they awaited routine follow-up clinic appointments. Individuals

Table 1 Sociodemographic and medical characteristics of sample and IIRS Subscale and Total scores

Characteristic	Prostate	Breast	Lymphoma	Head & Neck	Gastrointestinal	Lung
	<i>n (%)</i>					
Gender						
Men	119 (100.0)	–	57 (50.4)	53 (50.0)	53 (52.5)	47 (49.0)
Women	–	111 (100.0)	56 (49.6)	53 (50.0)	48 (47.5)	49 (51.0)
Marital status						
Single	7 (5.9)	14 (12.7)	15 (13.4)	14 (13.2)	9 (8.9)	8 (8.3)
Married/common-law	98 (82.4)	75 (68.2)	78 (69.6)	76 (71.7)	75 (74.3)	67 (69.8)
Separated/divorced/widowed	14 (11.8)	21 (19.1)	19 (17.0)	16 (15.1)	17 (16.8)	21 (21.9)
Education						
Grade 8 or less	8 (7.1)	5 (4.6)	5 (4.5)	6 (5.8)	3 (3.0)	7 (7.4)
Some/completed high school	40 (35.4)	41 (37.6)	38 (33.9)	37 (35.6)	24 (24.0)	39 (41.5)
College/university	36 (31.9)	46 (42.2)	49 (43.8)	45 (43.3)	44 (44.0)	27 (28.7)
Professional/graduate school	29 (25.7)	17 (15.6)	20 (17.9)	16 (15.4)	29 (29.)	21 (22.3)
Occupation**						
Worker for pay	41 (34.5)	46 (42.2)	65 (57.5)	57 (54.3)	50 (50.0)	24 (25.0)
Homemaker/student	0 (0.0)	18 (16.5)	12 (10.6)	9 (8.6)	10 (10.0)	10 (10.4)
Retired	77 (64.7)	32 (29.4)	17 (15.0)	25 (23.8)	27 (27.0)	44 (45.8)
Unemployed/disability	1 (0.8)	13 (11.9)	19 (16.8)	14 (13.3)	13 (13.0)	18 (18.8)
Tumor status**						
No tumor	46 (44.2)	62 (68.9)	44 (47.8)	55 (56.1)	41 (43.6)	46 (52.9)
Localized tumor	41 (39.4)	12 (13.3)	38 (41.3)	38 (38.8)	16 (17.0)	24 (27.6)
Metastatic tumor	17 (16.3)	16 (17.8)	10 (10.9)	5 (5.1)	37 (39.4)	17 (19.5)
	<i>M (SD)</i>					
Years of age**	66.99 (10.45)	56.71 (12.27)	52.39 (14.86)	50.97 (13.77)	56.56 (11.85)	62.08 (11.55)
Years since diagnosis*	5.30 (5.81)	6.11 (6.16)	5.51 (5.88)	4.01 (5.87)	3.08 (5.38)	4.03 (5.05)
	<i>M (SE)</i>					
Illness Intrusiveness Subscale Scores ^a						
Instrumental						
Men	2.48 (.19)	–	3.05 (.28)	3.19 (.25)	3.45 (.25)	3.80 (.28)
Women	–	3.02 (.19)	3.47 (.26)	3.22 (.27)	3.63 (.27)	3.62 (.28)
Intimacy						
Men	3.40 (.20)	–	2.65 (.29)	2.32 (.26)	3.01 (.26)	2.90 (.30)
Women	–	2.38 (.20)	2.40 (.28)	2.63 (.28)	2.47 (.29)	2.58 (.29)
Relationships & Personal Development						
Men	1.59 (.13)	–	1.95 (.19)	2.06 (.17)	2.36 (.18)	2.48 (.20)
Women	–	1.98 (.15)	2.40 (.20)	2.32 (.21)	2.46 (.21)	2.21 (.21)
Illness Intrusiveness Total Score (summed score) ^a						
Men	28.56 (1.76)	–	31.84 (2.55)	33.47 (2.29)	36.63 (2.30)	39.00 (2.60)
Women	–	31.20 (2.71)	36.59 (2.60)	35.56 (2.68)	37.83 (2.71)	36.31 (2.77)

^a Illness intrusiveness total and subscale scores are adjusted for covariates

p*<.01; *p*<.001

who met eligibility criteria received an introductory letter explaining the purpose of the study, participation requirements, and assuring anonymity and confidentiality. Those who volunteered provided informed consent before completing the questionnaires independently while awaiting their oncologists.

Statistical analyses

We calculated internal consistency reliability for the IIRS Total and subscale scores using Cronbach’s alpha. We calculated separate coefficients for each of the Cancer Type x Sex groups.

We tested the hypothesis that illness intrusiveness subscales would differ across cancer types using 2-way mixed Analyses of Covariance (ANCOVAs), with Cancer Type as the between-groups factor and IIRS Subscale as the within-groups factor. We conducted separate analyses for each sex. To compare the effect of cancer type on the IIRS Total Score, we conducted separate 1-way between-subjects ANCOVAs on the IIRS Total Score for each sex, with Cancer Type as the between-groups factor and IIRS Total Score as the dependent variable.

Covariates For all IIRS subscale- and total-score analyses, age, occupation, time since diagnosis, and tumor status (no evidence of disease, localized disease, or metastatic disease) were controlled as covariates. In addition, between-subjects ANOVAs were conducted on the remaining socio-demographic variables (sex, marital status, and education) to identify those significantly associated with each of the IIRS domain subscales ($p < .05$). A significant effect of marital status was observed for all three IIRS domains, p 's $< .01$; thus, marital status was added as a covariate for all analyses.

Results

Reliability (internal consistency) of the IIRS

Table 2 reports internal consistency estimates for all Sex x Cancer Type groups. Estimates for the IIRS Total and the Instrumental and Relationships and Personal Development subscales met the criterion of good internal consistency (Cronbach's $\alpha \geq .70$ [50] across all groups, α s = .78 to .93. For the Intimacy subscale, Cronbach's α was .40

for the Prostate group and ranged from .60 to .88 for the remaining Sex x Cancer Type groups.

Comparing illness intrusiveness across cancer types

Men with cancer The 2-way (Cancer Type x IIRS Subscale) mixed ANCOVA indicated a significant Cancer Type x IIRS Subscale interaction, $F(8, 496) = 6.97$, $p < .001$. Table 1 reports mean IIRS subscale scores, adjusted for covariates; these are plotted in Fig. 2. Significant pairwise differences ($p < .05$) were identified post-hoc by determining whether (a) within each cancer type, adjusted mean subscale scores fell outside the 95% confidence intervals of the other subscales and (b) adjusted mean scores of a subscale for one cancer type fell outside the 95% confidence intervals for the same subscale for the other types.

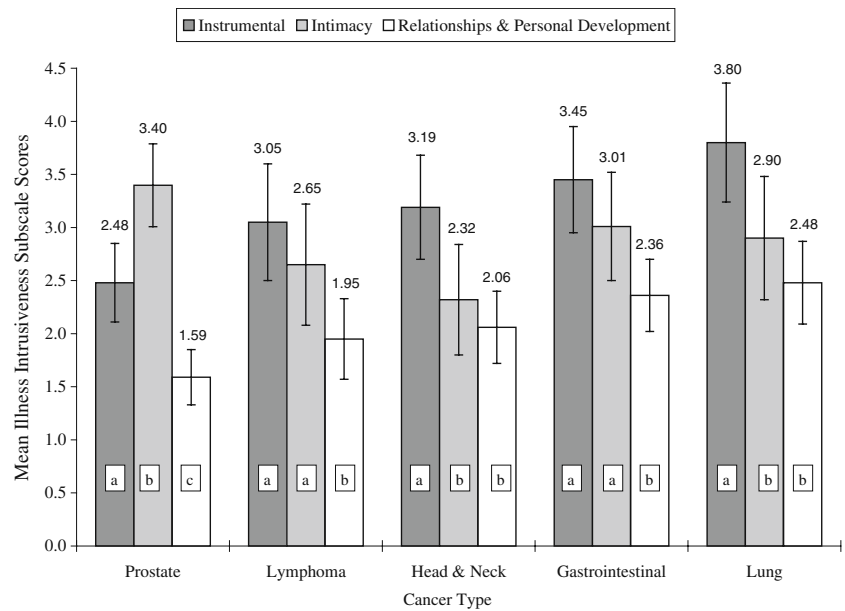
The first hypothesis, that all people with cancer will report the highest illness intrusiveness in the Instrumental domain, received partial support in men. As apparent in Fig. 2, Instrumental intrusiveness was highest of all three subscale scores for all cancer types, except prostate cancer. Relationships and Personal Development scores were the lowest for all cancer types. Post-hoc comparisons indicated that for all cancer groups, including prostate cancer, Instrumental scores were always significantly higher than Relationships and Personal Development scores, $p < .05$ (see Fig. 2). For head and neck and lung cancers, Instrumental scores were significantly higher than Intimacy scores, but Intimacy did not differ significantly from Relationships and Personal Development. For lymphoma and gastrointestinal cancers, on the other hand, Instrumental and Intimacy scores did not differ significantly, whereas Intimacy scores were significantly higher than Relationships and Personal Development scores.

Table 2 Internal consistency (Cronbach's α) coefficients for the IIRS Subscales and Total Scores across cancer types

Cancer type	Instrumental	Intimacy	Relationships and personal development	Total
Prostate	.79	.40	.78	.81
Breast	.88	.79	.81	.92
Lymphoma				
Men	.89	.66	.90	.92
Women	.79	.72	.84	.88
Head & Neck				
Men	.84	.63	.82	.90
Women	.83	.88	.84	.92
Gastrointestinal				
Men	.87	.72	.90	.93
Women	.80	.71	.89	.90
Lung				
Men	.92	.60	.83	.90
Women	.83	.66	.84	.90

Coefficients can range from 0.00 to 1.00, with higher values reflecting higher reliability

Fig. 2 Comparison of IIRS subscale scores across men with different cancer types, with confidence intervals formed by the standard errors. Mean IIRS subscale scores, adjusted for covariates, are indicated for each group. Within each cancer type, IIRS subscales marked with different letters (a–c) were significantly different, $p < .05$



The second hypothesis, that those with cancers that are more likely to affect sexuality and sexual functioning will report greater illness intrusiveness into Intimacy than those with other cancers, also received partial support in men. As evident in Fig. 2, Intimacy was the highest IIRS subscale score for prostate cancer, and it was significantly higher than both of the other subscale scores, $p < .05$. The prostate cancer group’s Intimacy score was also significantly higher than those for the male lymphoma and head and neck cancer groups, $p < .05$, but although it was also higher than the Intimacy scores for the gastrointestinal and lung cancer groups, differences were not statistically significant. Similarly, lung cancer, gastrointestinal cancer, and lymphoma did not differ significantly on Intimacy scores, but the gastrointestinal group did report significantly higher Intimacy disruption than the head and neck cancer group, $p < .05$.

Because of the relatively low reliability observed for Intimacy in the prostate cancer group (and male groups in general), a secondary analysis comparing the two Intimacy item scores was conducted for that group. A paired t -test indicated that for the prostate cancer group, the mean score for sex life, $M = 4.28$, $SD = 2.47$, was significantly higher than that for relationship with spouse, $M = 2.31$, $SD = 1.80$, $t(118) = 8.09$, $p < .001$. Similar analyses conducted with the other male cancer groups, to provide a context for interpreting this observation in prostate cancer, showed similar, but less extreme differences (in descending order of significance of difference): for gastrointestinal, $M_{\text{sex life}} = 3.57$, $SD = 2.41$ versus $M_{\text{relationship with spouse}} = 2.72$, $SD = 2.17$, $t(52) = 2.87$, $p = .01$; for head and neck, $M_{\text{sex life}} = 2.64$, $SD = 1.94$ versus $M_{\text{relationship with spouse}} = 1.96$, $SD = 1.44$, $t(52) = 2.77$, $p = .01$; for lung, $M_{\text{sex life}} = 3.30$, $SD = 2.51$

versus $M_{\text{relationship with spouse}} = 2.40$, $SD = 2.01$, $t(56) = 2.53$, $p = .02$; and for lymphoma, $M_{\text{sex life}} = 2.84$, $SD = 2.23$ versus $M_{\text{relationship with spouse}} = 2.37$, $SD = 1.85$, $t(56) = 1.73$, $p = .09$.

When we conducted the 1-way (Cancer Type) between-subjects ANCOVA for IIRS Total scores, results indicated a significant Cancer Type main effect in men, $F(4, 248) = 3.66$, $p = .01$. Table 1 presents adjusted total scores for each cancer group. The prostate cancer group reported the lowest mean Total score, whereas the lung cancer group reported the highest. Post-hoc pairwise comparisons indicated that the prostate cancer group reported significantly lower IIRS Total scores, $M = 28.56$, $SE = 1.76$, than the gastrointestinal cancer, $M = 36.63$, $SE = 2.30$, $p = .01$, and lung cancer groups, $M = 39.00$, $SE = 2.60$, $p = .001$. No other significant group differences were evident.

Women with cancer The 2-way (Cancer Type x IIRS Subscale) mixed ANCOVA showed only a significant IIRS Subscale main effect, $F(2, 474) = 4.39$, $p = .01$; there was no significant Cancer Type main effect or Cancer Type x IIRS Subscale interaction effect. Post-hoc pairwise comparisons across subscale scores indicated that illness intrusiveness differed significantly across all three subscales, p ’s $< .05$ to $< .001$. As hypothesized, women with cancer reported the highest score in the Instrumental subscale, $M = 3.39$, $SE = .11$, which differed significantly from both the Intimacy, $M = 2.49$, $SE = .11$, $p < .001$, and Relationships and Personal Development subscales, $M = 2.27$, $SE = .09$, $p < .001$. The latter two also differed significantly, $p = .03$, but hypothesized differences on the Intimacy subscale between breast and gastrointestinal cancers and other cancers were not observed.

The 1-way (Cancer Type) between-subjects ANCOVA on the IIRS Total score did not yield a significant Cancer

Type main effect in women, $F(4, 237)=1.40, p=.23$. Table 1 presents the adjusted total scores for each cancer group.

Discussion

As hypothesized, many men and women continue to experience cancer-related lifestyle interference to some degree long after the completion of cancer treatment; these effects are most pronounced when activities require physical and cognitive performance. This is consistent with other observations that ongoing side effects compromise physical and cognitive functioning [8, 28], but especially physical functioning [12], and this interferes with continued participation in activities that rely on such capacities [11, 13, 14, 29]. Thus, a number of long-term survivors continue to require medical management of side effects and other interventions to facilitate rehabilitation well after cancer treatment has concluded. The domain of employment would seem especially important to address because of its importance to identity, self-esteem, and life satisfaction [19, 51]. Difficulties in resuming employment during the period of long-term survivorship may also exacerbate the financial toll imposed by cancer treatment and by the unemployment often imposed on people while they undergo cancer [25, 52].

Prostate cancer survivors appear to be the exception, reporting less disruption in the Instrumental domain as compared to other aspects of life. This group may recover physical functioning more quickly than people with other cancers [53]. As expected, however, prostate cancer survivors reported more illness intrusiveness into Intimacy than men with lymphoma or head and neck cancer; they did not differ, however, from men with gastrointestinal or lung cancer. As hypothesized, men with gastrointestinal cancer also reported high illness intrusiveness into the Intimacy life domain but differed significantly only from men with head and neck cancer. These findings are consistent with numerous reports that iatrogenic neurovascular damage compromises erectile and ejaculatory functioning, sexual sensation, and satisfaction in prostate cancer [18, 31–33], and consequently compromises relationship adjustment and quality of life [18, 33, 54]. Male gastrointestinal cancer survivors similarly experience sexual dysfunctions due to pelvic-nerve damage, but also due to embarrassment about incontinence, odor and having an ostomy and ostomy appliance [13, 34, 35, 55]. In lung and, in fact, other cancer groups [56], psychological factors, like changes in appearance, self-perceived attractiveness [57], and mood [58], may contribute more strongly to reported sexual difficulties than physiological factors [56]. Sexual and relationship functioning are central to quality of life [59–61], and so

these issues should receive high priority during routine follow-up assessment. Physiological changes and changes in self-perceptions should both be investigated as contributors to sexual dysfunction [56].

Like their male counterparts, women with cancer reported the expected dominance of illness intrusiveness into Instrumental as compared to other life domains. Unlike men with prostate or gastrointestinal cancer, however, women with breast or gastrointestinal cancer did not differ from women with other cancer types in reported illness intrusiveness into Intimacy. Some studies have noted sexual dysfunctions and decreased libido in breast cancer survivors, particularly in those treated with chemotherapy [16, 37, 62], but others have not [63]. The nature and prevalence of sexual dysfunctions in gastrointestinal cancers are similarly less clear in women than in men [35, 64, 65]. However, intimacy issues should not be ignored in these groups because treatment sequelae such as loss of the breast (s), vaginal dryness, and dyspareunia can cause sexual difficulties and dissatisfaction [37]. It is crucial to realize that survivors may also be reluctant to report these distressing concerns. Sexual issues should be normalized through routine assessment, and appropriate medical and/or sex therapy initiated when indicated.

Overall, the separate IIRS subscales provide useful incremental information about psychosocial functioning over the IIRS total score. Men with prostate cancer reported the lowest total score of all male groups, but this obscures the specific adverse impact on intimacy. Total scores also mask the fact that the Instrumental domain is the most adversely affected domain and hence requires more urgent clinical attention in most cancer survivors. Hence, use of the subscale scores can provide a highly useful targeted screen in follow-up psychosocial assessments.

In terms of limitations, our respondent sample comprised outpatients with varied characteristics. This accurately reflects the diversity of clinical cohorts, but sample heterogeneity may affect the validity of group comparisons. We controlled statistically for group differences in background characteristics and for characteristics relating to illness intrusiveness, but findings nevertheless should be interpreted with caution and require replication. The relatively small subsample sizes, which may affect the power to detect group differences, also call for cross-validation with larger groups. Since participation rates were not recorded, representativeness is uncertain. However, healthier, less distressed individuals are more likely volunteer for studies [66]. Hence, our findings may both be more representative of such survivors and suggest that others may be worse off and in even more need of assessment and intervention. Regardless of the absolute representativeness of the patient groups, the fact cannot be ignored that a sizeable number of long-term cancer

survivors (>650 people) reported at least some ongoing interference with lifestyles activities and interests after treatment completion.

Other limitations include the caveat that causal priorities cannot be established due to the cross-sectional design. Finally, that individual scores on the two Intimacy-subscale items differed significantly in most male cancer groups, especially in prostate cancer, suggests that sexual and couple functioning may not always be disturbed to the same degree [67]. For certain groups, then (e.g., prostate cancer), separate clinical assessment of sexual and relationship adjustment may be warranted.

Cancer survivors who expect (or are expected) to resume “normal” lives following treatment may require more rehabilitative assistance than previously recognized. Patient-centered care and ongoing monitoring of participation in valued activities can help to redress quality-of-life concerns during long-term survivorship. Rehabilitative interventions can then be targeted to the concerns most likely to be associated with a specific cancer and/or treatment. The IIRS offers a brief, simple, and valid tool to screen for domain-specific lifestyle disruptions throughout survivorship and to evaluate the benefits of rehabilitative interventions.

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