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Sexual Functioning Among Young Adult Cancer Patients: A 2-Year Longitudinal Study

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Abstract

BACKGROUND—Cancer-related sexual dysfunction has been reported among adolescents and young adults (AYAs); however, its prevalence over time has not been examined. This longitudinal study investigated sexual dysfunction in AYAs over the course of 2 years after the initial diagnosis.

METHODS—Young adult patients (18–39 years old) completed the Medical Outcomes Study Sexual Functioning Scale within the first 4 months of their diagnosis (n = 123) and again 6 (n = 107) and 24 months later (n = 95). An ordered multinomial response model analyzed changes in

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AUTHOR CONTRIBUTIONS

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the probability of reporting sexual dysfunction over time and the independent effects of demographic, clinical, and psychosocial variables.

RESULTS—More than half of the participants reported sexual functioning to be problematic at each assessment. The probability of reporting sexual dysfunction increased over time ($P < .01$) and was greater for cancer patients who were female ($P < .001$), older ($P < .01$), married or in a committed relationship ($P < .001$), treated with chemotherapy ($P < .05$), and reporting comorbid psychological distress ($P < .001$) and lower social support ($P < .05$). For women, being in a relationship increased the likelihood of reporting sexual problems over time; for men, the likelihood of reporting sexual problems increased regardless of their relationship status.

CONCLUSIONS—A substantial proportion of young adults report ongoing problems with sexual functioning in the first 2 years after their cancer diagnosis. These findings justify the need to evaluate and monitor sexual functioning throughout a continuum of care.

Keywords

adolescents; adolescents and young adults (AYAs); cancer; sexual functioning; young adults

INTRODUCTION

Adolescents and young adults (AYAs) with cancer, as defined by the National Cancer Institute, are individuals between the ages of 15 and 39 years at diagnosis.[1] Considerable research has unveiled unique challenges experienced by AYAs, including poor quality of life, an altered body image, and social isolation.[2–4] As a result of these life disruptions, normative psychological and emotional development is affected by the disease and its treatment, particularly with respect to sexual identity, development, and behavior.[5] However, few studies have examined sexual functioning and AYA patients' needs with respect to emotional intimacy and sexual relationships.[6–8]

Cancer symptoms and treatment-related physical difficulties affect healthy sexual development among AYAs.[6,9] Nerve damage can cause erectile and ejaculatory dysfunction, reduce sexual desire, and impair the ability to reach orgasm in both men and women.[10] Younger women may be particularly vulnerable to the physiological effects of chemotherapy, which often induces early menopause, vaginal dryness, and dyspareunia.[11] Estimates of the prevalence of sexual dysfunction in AYAs are limited to date and vary because of data derived from mixed-age groups, single items instead of standardized instruments, and cross-sectional designs.7 Yet, the state of the science suggests that one-third to two-thirds of cancer patients experience sexual dissatisfaction and a reduced frequency of intercourse. [4,6,7] One prior study reported that 1 and 2 years after the diagnosis, the prevalence of sexual problems for AYAs was 49% and 43%, respectively.[7] Correlates of sexual problems include age, sex, relationship status, physical function, body image, and health-related quality of life.[6,7,12]

Sexual dysfunction describes a disorder that affects 1 or more phases of the human sexual response cycle[13] and potentially leads to psychological and relational distress.[14] Integrative models of sexuality that consider relational, psychological, cultural, and physiologic aspects

have emerged in cancer survivorship and direct this work.[10,13] Although prevalence rates of sexual problems have been reported for 30% to 50% of healthy adults15 and 44% to 57% of healthy adolescents,[16,17] recent research suggests that the implications of sexual dysfunction for young people diagnosed with cancer in their teenage and young adult years are different from those of healthy peers, childhood cancer survivors, and adult cancer patients. AYAs are more likely to enter committed partnerships and to start a family while facing cancer.[6,7] Furthermore, a failure to address sexual health may place AYAs at risk for long-term consequences related to sexual functioning and identity development,[18] interpersonal relationships,[4] and quality of life.[19] As such, detecting changes in the rate of sexual dysfunction over time may help in identifying the appropriate timing for interventions to be delivered. The current work extends our current knowledge of sexual functioning among AYAs by examining the prevalence of sexual dysfunction over the course of 2 years after the initial cancer diagnosis. It also aims to identify variables that contribute to sexual dysfunction in order to recognize individuals at higher risk.

MATERIALS AND METHODS

This study is part of a larger multisite, longitudinal investigation of psychosocial outcomes in a national sample of AYAs, with the study details reported elsewhere.[20] Institutional review board approval was obtained at the coordinating center and from each participating site.

Sample and Procedure

Serial recruitment over the course of 2 years (2008–2010) involved identifying young people who had been treated at 1 of 3 children's hospitals or 1 of 2 university-affiliated adult medical institutions in California, Oregon, and Texas; were 14 to 39 years old; had a first diagnosis of any invasive cancer; and were able to read and understand English or Spanish. Data were collected within 4 months of the diagnosis and again 6 and 24 months later. Young adult patients (≥18 years old) were administered the sexual functioning scale as part of the survey, and only those who completed the instrument at least once were included in this analysis. Hence, 123 participants composed the baseline sample. Five participants died between the first and second assessments, and complete data were available for 107 patients at the 6-month follow-up (a 13% attrition rate). When the survey was administered again 2 years after the baseline, 12 patients were deceased, and 95 returned the materials (a 22.7% attrition rate).

Measures

Sexual functioning—Sexual functioning was measured with the Medical Outcomes Study (MOS) Sexual Functioning Scale,[21] a validated instrument used to identify sexual impairment accompanying serious health conditions. Four items assess an individual's ability to be interested in sex and to achieve sexual arousal and orgasm. The scale is sensitive to sex differences, with 2 separate versions for males and females. Items are measured on a Likert scale ranging from 1 ("not a problem") to 4 ("very much a problem"). A fifth response category ("not applicable") indicates that the respondent is not sexually active, and this is recorded as "not a problem" according to manualized scoring instructions.

[22] The total score is obtained for males and females by the averaging of the sum of the items and then the transformation of the scores on a 0 to 100 scale, with higher scores indicating more impairment. Cronbach's α was .90 and .92 for men and women, respectively.[21]

Psychological distress—The Brief Symptom Inventory 18 (BSI-18) is a well-established instrument to screen for psychological distress.[23,24] It contains 18 items organized into 3 subscales (depression, somatization, and anxiety) and a summarized Global Symptom Index (GSI). A 5-point Likert scale (ranging from 0 ["not at all"] to 4 ["extreme"]) measures the extent to which a respondent has experienced distress over the past week. Raw scores are converted to age- and sex-adjusted T scores for comparison with community norms (mean, 50; standard deviation, 10), with higher scores indicating greater distress. A GSI score ≥ 63 suggests clinical distress and a need for assessment. Cronbach's α was .95 in the original study.[23]

Health-related quality of life—The 36-Item Short Form Health Survey (SF-36) assesses health-related quality of life.[25] The instrument includes 8 subscales: physical functioning, physical and emotional role limitations, bodily pain, social functioning, mental health, vitality, and general health perceptions. Subscale scores are standardized and then aggregated into physical and mental component scores, with higher scores indicative of better functioning. Data for summary scales are presented as T scores (mean, 50; standard deviation, 10). Cronbach's α was .90.[25]

Social support—Social support was investigated with the MOS Social Support Survey.[26] This is a questionnaire composed of 19 items that uses 5 response categories. Scores are calculated for 4 functional support scales and an overall social support index, with higher scores indicating greater social support. Only the total score was included in the analysis. Cronbach's α for the original scale was greater than .90.[26]

Demographic and clinical characteristics—Demographic measures, including sex, race, education, income, employment, and relationship status, were self-reported. Clinical data obtained from medical records included the age at diagnosis, cancer types, and treatment. Three categories of severity were created from Surveillance, Epidemiology, and End Results (SEER) codes: 1) diseases with expected 5-year survival rates greater than 80%, 2) diseases with expected 5-year survival rates between 50% and 80%, and 3) all other invasive malignancies with expected 5-year survival rates less than 50%.

Data Analysis

Descriptive statistics were used to summarize the sample at each time point. Then, single-item frequencies for sexual functioning by sex were computed (see Supporting Table 1). Because of the nonnormal distribution of the mean score of the outcome variable, a nonlinear analysis using an ordered multinomial response model with a log-link function was implemented to analyze changes in the probability of reporting sexual dysfunction over time, with the outcome variable treated as ordinal. Respondents with a total sexual function score ≤ 25 were assigned "not a problem," those with scores ranging from 26 to 50 were assigned "a little of a problem," those with scores ranging from 51 to 75 were assigned

"somewhat of a problem," and those with scores ≥ 76 were assigned "very much of a problem." Hierarchical generalized linear modeling (HGLM) with a backward selection method allowed to identify patterns within (level 1) and between individuals (level 2) and to test potential interactions.[27] The model fit was accomplished with Bayesian modeling and Markov Chain Monte Carlo (MCMC) estimation[28] with MLwiN 2.24.[29] Continuous variables were grand-mean centered to control for potentially problematic correlations among random components.[30] The model was allowed to vary on the intercept (level 2). The distribution of each variable, including outliers, was inspected and corrected to prevent any violation of functional form. No missing data existed for the second and third survey time points on the outcome measure.

At level 1, the outcome variable differed over time within individuals, and it was a function of time and individual-specific change parameters. At level 2, individual-specific change parameters were considered to vary between subjects and were modeled as a function of variables differing between individuals. Time-variant variables within patients (level 1) included relationship status, employment, treatment type, psychological distress, summary measures of physical and mental health-related quality of life, and social support. Time-invariant variables (level 2) included sex, race, education, age at diagnosis, and severity of disease. The model fit was accomplished first by the estimation of the unconditional mean model (model A), which simply described and partitioned the outcome variation. Time was then added to estimate the unconditional growth model (model B), where change in the outcome variable was described over time. Then, the conditional growth model with time-invariant and time-variant main effects (model C) was estimated, and finally, the conditional growth model with main and interaction effects (model D) was estimated.

RESULTS

Demographic, clinical, and psychological measures are summarized in Table 1. Participants mostly were men (53.7%), were non-Hispanic white (52.8%), were diagnosed with cancer in their late 20s (mean, 29.2 years), and had received treatment including chemotherapy (71.5%). At the baseline, most young adults were involved in a romantic relationship (57.7%). At the 6-month follow-up, the proportion declined to approximately 40%, and 2 years after the diagnosis, 43.2% of the participants were partnered. Psychological distress increased over time, with the mean GSI score ranging from 57.1 at the baseline to 68.3 at the last follow-up. Both physical and mental components of health-related quality of life improved over time; however, they remained below the standardized population mean. Rates of social support remained elevated over time.

At the baseline and the 6-month follow-up, more than half of all young adult patients (52% and 54.2%, respectively) reported some degree of problem with sexual functioning. After 2 years, more than half of the sample (52.6%) still reported some degree of affected sexual functioning (Table 2). Results of the ordered multinomial response model (Table 3) indicate that increased probabilities of sexual dysfunction were reported over time ($P < .01$). In this sample, a significant main effect of sex was detected, with women presenting with a higher likelihood of reporting sexual problems than men ($P < .001$). Worse sexual functioning was predicted for older cancer patients ($P < .01$), with young adults at the 90th percentile of age

(38 years) more likely to report sexual dysfunction than younger participants (10th percentile, approximately 19 years). In addition, young adults who were involved in a relationship with a partner were estimated to have higher probabilities of experiencing sexual dysfunction ($P < .001$). Among clinical factors, cancer patients who received chemotherapy had an increased chance of sexual problems ($P < .05$). Higher psychological distress was significantly associated with increased probabilities of sexual dysfunction ($P < .001$). On the contrary, social support was predictive of a reduced likelihood of sexual problems ($P < .05$). Finally, 2 significant interactions were identified: a 2-way interaction of severity of cancer by sex ($P < .01$) and a 3-way interaction of time by sex and relationship status ($P < .05$). Although among women with higher survival rates the probabilities of reporting sexual functioning as problematic were similar, worse sexual outcomes were predicted for those with a survival rate less than 50% (Fig. 1). For males, probabilities were similar across the 3 groups. Figure 2 presents the predicted probabilities of sexual dysfunction over time for the 2 sexes by relationship status. For women, being in a relationship increased the likelihood of reporting sexual problems over time in comparison with not being in a relationship; for men, reporting sexual problems over time increased regardless of their relationship status.

DISCUSSION

Following earlier research indicating that 43% of patients reported an affected sexual life 2 years after diagnosis,[7] the current study provides further evidence that substantial portions of young adults continue to struggle with sexual functioning over time. The rates of sexual dysfunction observed here are consistent with those found in other studies. Among male survivors of lymphoma, sexual dysfunction ranged from 20% to 54% across studies,[31] whereas for testicular cancer patients, the percentages varied from 11% for loss of desire to 51% for ejaculation problems.[32] Up to 52% of young breast cancer patients were found to experience sexual problems[33] and to present with poorer sexual function in comparison with both older survivors and age-matched control groups.[34] In a cross-sectional study of sexual satisfaction and quality of close relationships among young German patients, one-third of the sample members were not satisfied with their sexual life and frequency of intercourse.[6] However, our participants reported a higher prevalence than those in the work by Wettergren et al[7]; this result may be partially explained by the different measures (dichotomous item vs questionnaire). The MOS Sexual Functioning Scale has been previously used in cross-sectional studies to assess sexual problems in childhood cancer survivors[35] and has been validated with adults faced with medical conditions.[21,22] Our participants reported a greater prevalence of sexual dysfunction than childhood cancer survivors (42.7%); however, in the validation study of the scale, 59% of the sample reported sexual problems.[21,22] Despite these differences, our results confirm that sexual functioning of young adults is significantly affected by cancer, with implications for the well-being of the individual that extend beyond active treatment.

Female sex was associated with higher probabilities of sexual dysfunction, especially for those with a 5-year survival rate less than 50%. Although few studies have analyzed sex differences in the presentation of sexual dysfunction among AYAs, the worse outcomes observed for women are consistent with data from the existing literature.[8,36–38] Notably, a

study revealed that more than 70% of young female survivors experience a reduced frequency of sexual intercourse after diagnosis.6 Our findings are also similar to the work of Champion et al,[34] who identified a pattern of decreased interest, arousal, and frequency of orgasm. Sexual difficulties in young women with breast cancer begin after surgery, and although for some they gradually decrease, sexual functioning remains problematic 1[39] and 5 years later.[40]

The probability of sexual problems increased over time for all young adults; however, when we accounted for the relationship status, sexual problems worsened for women who were married or in a relationship, whereas for men, sexual dysfunction worsened regardless of their relationship status. This suggests that sexual functioning is experienced differently by sex. Although the results confirm that sexual problems are reported by cancer patients involved in a relationship,[12,35] the diverging trends for women and men not in a relationship direct the attention toward male patients because this group may be at higher risk for long-term sexual problems. Our findings reflect the complexity of adjusting and coping with cancer for young adults, and we recommend additional research to examine the differential effects of cancer on sex and sexuality for men, women, and transgender young people.

Older age, chemotherapy, and psychological distress were predictive of the probability of reporting sexual dysfunction, whereas social support had a protective effect in this sample. Worse outcomes for young adults confirm the more detrimental effect of cancer on their sexual functioning.[4,7] Similarly, the previous linkage of chemotherapy with sexual dysfunction, either direct or due to treatment-related consequences, was confirmed.[31,41] Future research is needed to determine the extent to which biological, neurological, and psychological mechanisms interact in this population. Young adults reporting high psychological distress had greater probabilities of worse sexual functioning,[12,42,43] but no significant role was played by health-related quality of life; a lack of significance similar to the results from the AYA Health Outcomes and Patient Experience study.[7] Finally, the relevance of supportive networks for this group[9] is represented by the result for perceived social support.

Some limitations affect the current study. First, more frequent assessments would have provided more accurate estimates of sexual dysfunction. Second, the MOS Sexual Functioning Scale focuses on performance indicators but excludes satisfaction with sexuality and associated distress. Because addressing sexual problems in the context of cancer requires an integrative approach,[10] a multidimensional measure should have been considered. Attrition rates confirm the challenges of recruiting and following up with AYAs.[44] Studies that actively promote subject retention are needed. Finally, the study did not include a matched-control group and, therefore, lacks the ability to compare current findings with normative data.

Approximately half of young adult cancer patients experienced some degree of sexual dysfunction for up to 2 years after the diagnosis, which reached moderate to severe levels for nearly one-quarter of the sample. Time, demographic, clinical, and psychosocial variables contributed to reporting sexual problems. Embarrassment and limited training among providers have contributed to the current lack of attention for sexual dysfunction among

AYAs.[20,45] This study emphasizes the need to implement protocols that monitor sexual functioning throughout a continuum of care and connect patients to psychosocial interventions alleviating the life disruptions caused by cancer and its treatment.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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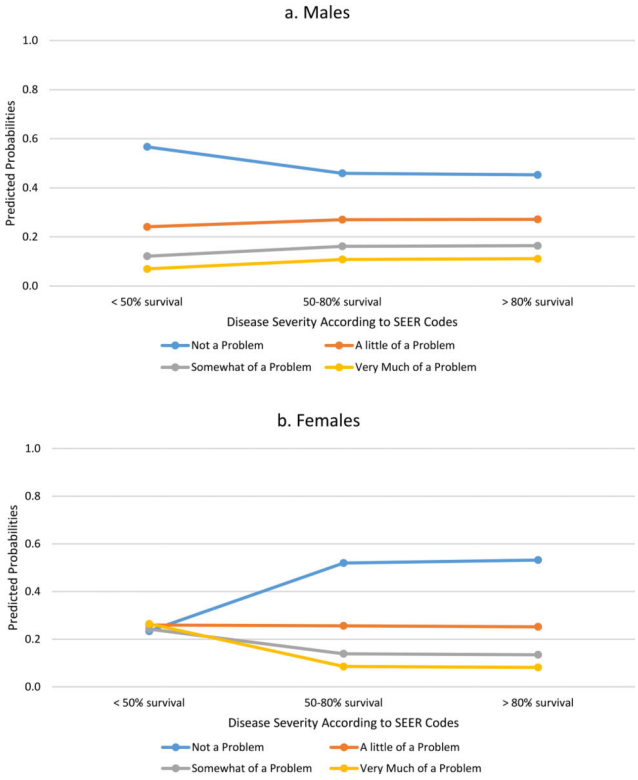

Figure 1.

Predicted probabilities of reporting sexual dysfunction by severity of cancer for the 2 sexes. SEER indicates Surveillance, Epidemiology, and End Results.

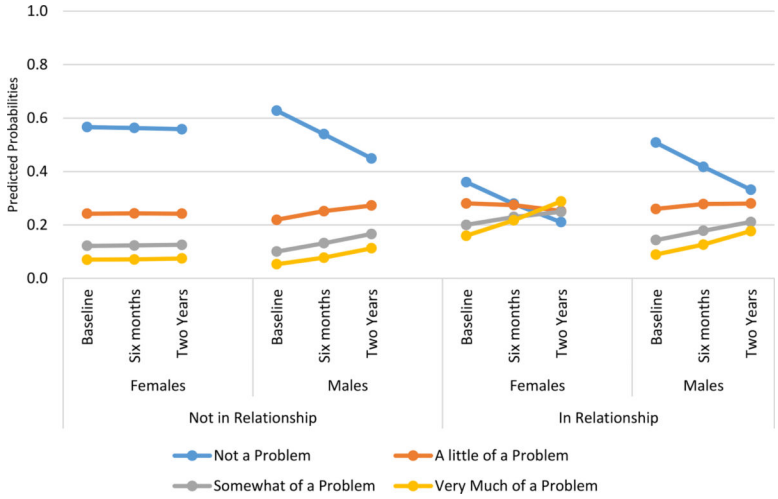

Figure 2.

Predicted probabilities of reporting sexual dysfunction over time by sex and relationship status.

TABLE 1.

Sample Demographic, Clinical, and Psychosocial Characteristics

Characteristic	Baseline (n = 123)	6-mo Follow-Up (n = 107)	24-mo Follow-Up (n = 95)
Demographic characteristics			
Sex, No. (%)[a]			
Male	66 (53.7)		
Female	57 (46.3)		
Relationship status, No. (%)			
Yes	71 (57.7)	42 (39.3)	41 (43.2)
No	50 (40.7)	63 (58.8)	50 (52.6)
Race, No. (%)[a]			
Non-Hispanic white	65 (52.8)		
Hispanic/Latino	43 (35.0)		
Other	14 (11.4)		
Education, No. (%)[a]			
High school or less	47 (38.2)		
Some college or more	76 (61.8)		
Income, No. (%)[a]			
≤$25,000	58 (47.2)		
>$25,000	63 (51.2)		
Employment/school status, No. (%)			
Not occupied	71 (57.7)	53 (49.5)	34 (35.7)
Occupied	48 (39.0)	51 (47.7)	56 (59.0)
Clinical factors			
Age at diagnosis, mean (SD), y	29.2 (7.1)		
Age at diagnosis (categorical), No. (%)			
18–25 y	43 (35.0)		
26–39 y	80 (65.0)		
Severity of cancer (% of survival), No. (%)[a]			
<50%	32 (26.0)		

Characteristic	Baseline (n = 123)	6-mo Follow-Up (n = 107)	24-mo Follow-Up (n = 95)
50%–80%	49 (39.9)		
>80%	42 (34.1)		
Cancer type, No. (%)[a]			
Leukemia	19 (15.4)		
Breast	18 (14.6)		
Soft-tissue sarcoma	15 (12.2)		
NHL	13 (10.6)		
Bone	10 (8.1)		
Testicular	10 (8.1)		
Hodgkin disease	9 (7.3)		
Female genital	7 (5.7)		
Brain	6 (4.9)		
Other	15 (12.3)		
Treatment, No. (%)			
Chemotherapy (y)	88 (71.5)	42 (39.3)	24 (25.3)
Radiation (y)	23 (18.7)	3 (2.8)	—
Surgery (y)	30 (24.4)	12 (14.0)	22 (23.2)
Psychosocial variables			
Psychological distress: Global Symptom Index			
Mean (SD)	57.1 (10.8)	55.1 (11.2)	68.3 (5.8)
Range	33.0–81.0	33.0–81.0	61.0–81.0
Quality of life			
SF-36 physical component			
Mean (SD)	39.9 (10.4)	39.6 (10.5)	40.0 (10.1)
Range	13.7–59.6	13.8–62.0	13.7–61.9
SF-36 mental component			
Mean (SD)	40.8 (13.6)	43.0 (13.0)	43.2 (11.1)
Range	8.0–67.2	9.9–67.2	18.2–63.8
Social support: MOS social support overall index			
Mean (SD)	4.2 (0.9)	4.2 (0.9)	4.0 (1.0)
Range	1.0–5.0	1.0–5.0	1.0–5.0

Abbreviations: MOS, Medical Outcomes Study; NHL, non-Hodgkin lymphoma; SD, standard deviation; SF-36, 36-Item Short Form Health Survey.

[a] The variable was measured only at the baseline.

Not all groups of n values and % add up to the reported sample size for each assessment because of missing data.

TABLE 2.

Sexual Functioning Groups Obtained From the Total Scores on the Medical Outcomes Study Sexual Functioning Scale

	Baseline (n = 123)	6-mo Follow-Up (n = 107)	24-mo Follow-Up (n = 95)
Sexual functioning not a problem, No. (%)	59 (48.0)	49 (45.8)	45 (47.4)
Sexual functioning a little of a problem, No. (%)	31 (25.2)	26 (24.3)	17 (17.9)
Sexual functioning somewhat of a problem, No. (%)	14 (11.4)	21 (19.6)	14 (14.7)
Sexual functioning very much of a problem, No. (%)	19 (15.4)	11 (10.3)	19 (20.0)

TABLE 3.

Multilevel Models Predicting the Probability of Reporting Sexual Dysfunction Over Time (n = 325)

Parameter	Model A	Model B	Model C	Model D
Fixed part				
Constant ($\beta_{0.012jk}$)				
Sexual functioning not a problem	−0.09 (0.2)	0.21 (0.4)	0.21 (0.6)	1.44 (0.7)[a]
Sexual functioning a little of a problem	1.32 (0.2)[c]	1.66 (0.4)[c]	1.80 (0.6)[b]	3.04 (0.7)[c]
Sexual functioning somewhat of a problem	2.59 (0.3)[c]	2.95 (0.5)[c]	3.23 (0.7)[c]	4.49 (0.8)[c]
Time ($\beta_{1.012jk}$)		−0.16 (0.1)	−0.42 (0.2)[a]	−0.50 (0.2)[b]
Female ($\beta_{2.012jk}$)			−0.33 (0.4)	−2.51 (0.7)[c]
Age ($\beta_{3.012jk}$)			−0.08 (0.1)[b]	−0.07 (0.1)[b]
Not in a relationship ($\beta_{4.012jk}$)			1.15 (0.3)[c]	0.68 (0.4)
Chemotherapy ($\beta_{5.012jk}$)			−0.67 (0.3)[a]	−0.73 (0.3)[a]
Global Symptom Index ($\beta_{6.012jk}$)			−0.06 (0.1)[c]	−0.06 (0.1)[c]
MOS Social support overall index ($\beta_{7.012jk}$)			0.42 (0.2)[a]	0.37 (0.2)[a]
Severity of cancer 50%−80% of survival ($\beta_{8.012jk}$)			0.60 (0.5)	−0.60 (0.6)
Severity of cancer >80% of survival ($\beta_{9.012jk}$)			0.53 (0.5)	−0.63 (0.6)
Female × severity of cancer 50%−80% of survival ($\beta_{10.012jk}$)				2.36 (0.8)[b]
Female × severity of cancer >80% of survival ($\beta_{11.012jk}$)				2.44 (0.9)[b]
Time × female × not in a relationship ($\beta_{12.012jk}$)				0.48 (0.2)[a]
Random parameters				
Level 2: between persons				
Constant/constant (σ^2_{v012})	2.7 (0.8)	2.9 (0.9)	2.4 (0.9)	2.1 (0.8)
−2 × log likelihood				
DIC	758.0	757.9	721.3	717.9
pD	89.9	93.5	86.3	82.1
Units: Individual	154	154	154	154

Parameter	Model A	Model B	Model C	Model D
Units: Time	325	325	325	325
Units: Responses	975	975	975	975

Abbreviations: DIC, deviance information criterion; *pD*, effective number of parameters.

[a] $P < .05$.

[b] $P < .01$.

[c] $P < .001$.