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Stress and marital adjustment in families of children with cancer

Iris Lavi¹, Kaitlyn Fladeboe², Kevin King², Joy Kawamura³, Debra Friedman⁴, Bruce Compas⁵, David Breiger³, Kyriell Gurtovenko², Liliana Lengua², Lynn Fainsilber Katz²

¹The Center for Research and Study of the Family, School of Social Work, University of Haifa, Haifa, Israel

²Department of Psychology, University of Washington, Seattle, WA, USA

³Seattle Children's Hospital, Seattle, WA, USA

⁴Department of Pediatrics, Vanderbilt University, Nashville, TN, USA

⁵Department of Psychology, Vanderbilt University, Nashville, TN, USA

Abstract

Objective: Pediatric cancer is highly stressful for parents. The current prospective study examines the impact of several stressors (financial strain, life threat, treatment intensity, treatment-related events, and negative life events) on the trajectory of marital adjustment across the first year following diagnosis. We examined whether average level of stressors across the year was related to (1) levels of marital adjustment at the end of the first year of treatment and (2) the rate of change in marital adjustment.

Method: One hundred and thirty families of children newly diagnosed with cancer (M age = 6.33 years, $SD = 3.61$) participated. Primary caregivers provided 12 monthly reports on marital adjustment and stressors.

Results: Multilevel models indicated that although marital adjustment was stable across the first year on average, random effect estimates suggested that this was the result of differing trajectories between families (eg, some increasing and others decreasing). Five individual stress constructs and a cumulative stress composite were then used to predict this variability. Higher average economic strain was related to consistently poorer marital adjustment across time. Higher average frequency of treatment-related events and negative life events were associated with decreasing adjustment over time and lower adjustment at the end of the first year of treatment. Perception of life threat and treatment intensity were not associated with final levels or trajectory of adjustment. Finally, higher cumulative stress was associated with consistently poorer marital adjustment across time.

Conclusion: Implications for identification of at-risk families are discussed, and importance of delivering tailored interventions for this population.

Keywords

economic strain; life threat; marital adjustment; pediatric cancer; stress; treatment

Correspondence Iris Lavi, The Center for Research and Study of the Family, School of Social Work, University of Haifa, Haifa, Israel. iris.lavi.01@gmail.com.

1 | BACKGROUND

A diagnosis of childhood cancer is highly stressful and impacts not only individuals within the family but also relationships between family members.^{1,2} Emerging evidence suggests that 1 of the areas of family relations that is impacted is the marital relationship.³ Given the central role of the marital subsystem to both family and child adjustment,⁴ attention has been given to examining changes in marital adjustment through the treatment process,⁵ as well as predictors of such change.⁶ The current study aims to extend this area of research to assess the influence of stress.

Studies examining marital relations in families of children with cancer have identified several trends. Some noted a decrease in marital relationship quality,^{7,8} particularly in the area of intimacy.⁹⁻¹² Other found improvements in the marital relationship¹³ or that partners reported stable levels of relationship quality.¹¹

One explanation for these conflicting conclusions is that there may be considerable interfamily variability. Indeed, Katz et al¹⁴ recently reported individual differences in the trajectory of marital adjustment across the first year of treatment such that some families remained stable, some declined, and some improved. Thus, an important next step is to identify what factors predict differential trajectories of marital adjustment between families. Given the high levels of stress inherent in the diagnosis and treatment of pediatric cancer, stress may be one such determinant. In the current paper, we examine a combination of cancer-specific and general stressors that have been identified in families with cancer but have not been examined as predictors of marital satisfaction in this population.

Families face many stressors as they weather the treatment process. These may include financial burdens,^{15,16} strain resulting from perceptions of life threat to the child,¹⁷ the intensity of treatment and other aspects of the treatment,^{18,19} and other negative life events.^{17,20} Studies have shown that financial strain is a significant cause of distress among parents of children with cancer.^{15,16,21,22} Other cancer-related stressors have been studied, but to a lesser degree. Stressors that relate to the child's treatment have been noted to influence parental well-being.^{18,19} Both perception of life threat and intensity of treatment have been linked to post-traumatic reactions in parents.¹⁷

In comparison to healthy controls, parents of children with cancer report more stressful events that are unrelated to the illness,²⁰ including illness or injury to other family members.¹⁷ Most stressors reportedly occur within the period directly following diagnosis.^{23,24} As studies have linked normative stressful events to a decline in relationship quality, it would be reasonable to expect that a highly stressful, non-normative event such as a diagnosis of cancer in a child would be associated with a decline as well.

We explored the impact of specific stressors on the trajectory of marital adjustment during the first year of pediatric cancer treatment. Given the important role of subjective processing to the stress experience,²⁵ the study addresses caregiver's perceptions of stress. Determining which specific stressors influence the trajectory of marital adjustment has the potential to inform policy makers and professionals as to which families most need intervention and to allow them to design intervention to target those specific stressors that impact well-being.

The first year following diagnosis was examined as it has been identified as the most stressful for families and may reflect their greatest efforts to retain normative family life.²⁶

We first examined the average trajectory of marital adjustment. Next, we examined whether 5 stressors would predict differences in that trajectory. Each stressor (financial strain, life threat, treatment intensity, treatment-related events, and negative life events) was examined individually as there is little research on exactly which predictors have the most detrimental effect on the trajectory of marital adjustment. We believe it is theoretically important to understand the unique impact of each stressor so that targeted interventions can be developed to address the specific stressors that have the most detrimental effect. Given the considerable research on the impact of cumulative stress,²⁷ we also examined the 5 stressors in combination. We examine whether this construct of multiple, co-occurring stressors determines whether families show differential trajectories in marital adjustment. For each individual stressor, and for cumulative stress, we hypothesized that higher average levels of stress across the first year of treatment relative to other families would be associated with declines in the trajectory of marital adjustment over time, and lower levels of marital adjustment at the end of the first year of treatment. In addition, we hypothesize that higher cumulative stress across the first year of treatment relative to other families would be associated with declines in the trajectory of marital adjustment over time, and lower levels of marital adjustment at the end of the first year of treatment.

2 | METHOD

2.1 | Participants

Families were recruited as part of a larger study examining pediatric cancer and family adjustment. Of 502 eligible families, 309 were approached, 176 enrolled, and 159 completed at least 1 study component. The most common reason for decline was that the family was too busy. Data was used from 130 families in which caregivers were married or romantically involved, with 118 completing the initial questionnaire (91%). At subsequent time points, the highest proportion of primary caregivers were retained at month 6 (66.15%), and the lowest at month 2 (5.38%), followed by 43.08% at month 3. Number of completed packets was not correlated with any demographic variables, including parent age, child age, child gender, diagnosis, marital status, or income. In addition, the number of completed packets was not correlated with marital adjustment across the 12 time points, with 2 exceptions: with marital adjustment at T2 ($r = .22$, $P = .02$) and with marital adjustment at T10 ($r = .39$, $P = .003$). Lastly, the number of completed packets was not correlated with any of the stress variables across the 12 time points, with 3 exceptions: treatment intensity T4 ($r = .24$, $P = .02$), treatment intensity T8 ($r = .25$, $P = .03$), and treatment-related events ($r = .27$, $P = .02$). Because these correlations represent higher number of completed packets when stress is higher, it is not an indication that there is greater dropout with higher stress.

Families were approached within 2 weeks of diagnosis, and the first questionnaire packet was completed between 2 weeks and 4 months post diagnosis ($M = 55.23$ days, $SD = 26.53$). Children with cancer were between the ages 2 to 17 (M age = 6.33 years, $SD = 3.61$; range = 2-17 years, 49% male). Most children were diagnosed with leukemia (38.5%), followed by CNS tumor (24.6%), lymphoma (10.0%), sarcoma (10.0%), Wilm's tumor (6.9%),

neuroblastoma (3.1%), or another form of cancer (6.9%). The majority of children were White/ Caucasian (86.3%). Primary caregiver was identified as the mother (87.2%), father (10.4%), grandmother (1.6%), or stepmother (0.8%). Analyses were performed using both the full sample and a sample including only mothers, to verify that the role of the primary caregiver in the family is not a meaningful covariate. Because results are similar in both analyses, the full sample was retained. Average age of primary caregiver was 36.02 years ($SD = 7.74$). Caregivers were either married (90.8%) or romantically involved but not married (9.2%). Among married couples, average length of marriage was 10.15 years ($SD = 6.0$). On average, families had 2.4 children ($SD = .91$). Incomes of \$40,000 or less, between \$40,000 and \$80,000, and over \$80,000 were reported by 32.5%, 26.2%, and 41.3% of the sample, respectively.

2.2 | Procedure

Participants were recruited through new diagnosis registries from 2 children's hospitals in urban areas of the Northwest and Southeast USA. Families were approached if they had a child who was newly diagnosed with cancer and had no history of developmental delay. Initially approached by their physician or nurse, families who were interested in participating were contacted by a member of the research team, and consent and Health Insurance Portability and Accountability Act of 1996 authorization were obtained. All families were English speaking. Data were collected over a 12-month period beginning with an initial caregiver questionnaire packet distributed at the time of consent, followed by monthly packets distributed and returned by mail. Packets were completed by primary caregivers.

2.3 | Measures

2.3.1 | Marital adjustment—The Dyadic Adjustment Scale²⁸ was used to assess marital adjustment. This 35-item scale yields an overall Dyadic Adjustment score, which is computed as a sum of all items, with higher scores indicating better adjustment. This measure has been validated for use with parents of chronically ill children²⁹ and was found to be sensitive to changes in marital adjustment over time in longitudinal studies.²⁵ Scores below 107 represent marital adjustment that is mildly distressed.³⁰ Cronbach's alpha in our sample ranged from .91 to .97, with an average of .96 across the 12 time points.

2.3.2 | Financial strain—The 10-item Economics In My Family Questionnaire³¹ used is generally based on the Psychological Sense of Economic Hardship Scale, reported in Barrera et al,³¹ and based on Conger and Elder³² and their adaptations of earlier scales.^{33,34} Items referring to cancer-related financial stress were also included. Participants were asked about economic adjustments they have made and level of worry about finances. Items were scored on a 3-point or 5-point Likert scale and were summed (using *z* scores) to form an overall score of financial strain. Higher scores represent greater strain. Cronbach's alpha ranged from .83 to .91, with an average of .88 across time points.

2.3.3 | Life threat and treatment intensity—Primary caregiver perceptions of child's life threat and treatment severity were assessed using the 4-item Assessment of Life Threat and Treatment Intensity Questionnaire,³⁵ which has been used widely in studies of pediatric

cancer.¹⁷ Two items measuring perceived life threat were summed to yield an overall Perceived Life Threat score, and 2 items measuring treatment intensity were summed to yield an overall Perceived Treatment Intensity score. For Perceived Life Threat, Spearman-Brown reliability coefficients ranged from .66 to .84, with an average of .77 across time points. For Perceived Treatment Intensity, coefficients ranged from .52 to .91, with an average of .78 across time points.

2.3.4 | Treatment-related events—The Treatment-Related Events Questionnaire³⁶ includes 24 items addressing treatment procedures and treatment stressors. Primary caregivers indicated how often each event occurred within the past month (1 = never, 5 = very often). Of the 24 items, 9 consist of cancer treatment-related procedures (eg, chemotherapy, lumbar punctures) and 15 consist of treatment stressors (eg, long hospital stays). A summed score of overall frequency of all treatment-related events was used. Higher scores represent greater frequency of events.

2.3.5 | Negative life events—An adapted version of the General Life Events Schedule for Children³⁷ was used to measure the frequency of negative life events families experienced within the past month. Items were adapted for use with primary caregivers, who reported on frequency of occurrence of 18 moderate to severe events, such as injury or job loss. The scale yielded a total negative events score. Because 1 item addressed parental divorce and/or separation, which may be confounded with our outcome variable, 2 additional steps were taken. First, we verified that the complete scale and the scale without this item are highly correlated (across the 12 time points, the lowest correlation was .995, and 6 correlations were 1.00). Second, we recalculated the analysis, dropping the item in question. Because results were similar using the scale without the item on separation/divorce, the original scale was retained.

2.4 | Data analytic strategy

Hypotheses were examined using growth curve models in a multilevel modeling (MLM) approach, using the maximum likelihood (ML) estimator in SPSS 18.0. Data from 12 monthly assessments were used to estimate trajectories. Multilevel modeling growth models allow trajectories to be estimated from different numbers of observations per family despite missing data, so all available data were included in analyses.

Before testing predictors, initial growth models were conducted to establish the average trajectory of marital adjustment and variability in that trajectory. For all models, time was coded from -11 (baseline) to 0 (month 12) for a total of 12 time points. The intercept parameter in all models is the level of marital adjustment at time 12. Modeling followed 3 steps. In the first step, an unconditional growth model was estimated with a linear time function. This model estimated a fixed intercept parameter, representing the average final level of marital adjustment as well as a fixed linear slope parameter, representing the average rate and direction of linear change in marital adjustment (ie, increase or decrease). In the second step, random effects were added for intercept and slope to test whether there were between-family differences in final levels or rate of change as indicated by an improvement in model fit. Model fit comparisons were done by calculating -2LL differences between

models and comparing the Akaike information criteria and Bayesian information criteria.³⁸ If model fit improved, this would suggest sufficient between family variance to test potential predictors that may account for these differences.

In the third step, 5 stress predictors were tested. Each predictor was tested separately for 2 reasons. First, although no specific hypotheses about the unique effects of each type of stressor were proposed, the theoretical importance of examining each stressor separately informed our data analysis. Second, testing each predictor separately avoided potential problems because of multicollinearity. Individual stress predictors were grand-mean centered to reflect the average level of stress a given family experienced over the first year of treatment relative to other families (ie, positive scores indicated more average stress than other families). Main effects of these predictors represent how average level of stress relative to other families relates to levels of marital adjustment at the end of the year. Interaction estimates represented whether and how a family's average stress level relative to other families affects their trajectory of marital adjustment.

Finally, to understand whether greater overall stress was associated with marital adjustment, we examined cumulative stress by creating a variable representing overall stress levels. This was done by using the percent of maximum possible method³⁹: Each of the 5 variables was transformed to a unified scale, such that the possible minimum is represented by 0 and the possible maximum is represented by 1 (eg, a scale of 1 to 4 would be transformed to a scale of 0 to 1). The cumulative stress predictor was also grand-mean centered to reflect the average level of stress a given family experienced relative to other families.

3 | RESULTS

Table 1 presents descriptive information for marital adjustment at each time point. Most parents reported high levels of marital adjustment, with more than 70% above the cutoff point of marital distress at any given time point. For model building and fit information, see Table 2. Because of low response rate at T2, models were examined while excluding T2, resulting in similar patterns of results; thus, the full range of time points was retained. Results indicated that a fully random linear growth model improved fit compared to fully fixed and random intercept models. In this final model, no linear effect of time was found. On average, families' final level of marital adjustment was 119.09 ($SE = 2.77$, $P < .001$), and *on average*, families did not change over time. However, random effects suggested variability existed in both intercept (final levels of marital adjustment) and slope (rate of change over time).

In other words, families show significant variance in initial level of marital adjustment, with initial levels ranging between 90.12 and 148.06 for 68% of the sample, and rates of change varied from -1.23 to 1.27 . Thus, while the aggregate rate of change was not statistically significant, this was a result of families changing in opposite directions over time. For example, because change was at the 1-month level, a couple at $1SD$ below the mean on rate of change in adjustment would show decreases in adjustment of about 15 points over the study period (1 year), whereas a couple at $1SD$ above the mean on rate of change in adjustment would be expected to increase by about 15 points.

Five stress predictors were then separately tested. For economic strain, treatment-related events, and negative life event models, inclusion of predictors resulted in better model fit than the basic growth model (see Table 2), suggesting that these stressors explain some variance in marital adjustment. For economic strain, a main effect was found, indicating that families with high average economic strain relative to other families had lower marital adjustment at the end of the first year of treatment ($b = -1.13$, $SE = .43$, $P = .01$; see Figure 1). For treatment-related events, a main effect and interaction effect were found, such that higher average frequency of treatment events relative to other families was associated with lower marital adjustment at the end of the first year ($b = -.56$, $SE = .18$, $P = .002$), and families with higher average levels of treatment events relative to other families declined more rapidly in marital adjustment over time. For general negative life events, a main effect and interaction effect were found, such that higher average frequency of general negative life events relative to other families was associated with lower marital adjustment at the end of the first year ($b = -10.99$, $SE = 2.06$, $P < .001$) and families with higher average frequency of negative life events declined in marital adjustment over time, whereas those with lower average negative life events increased in marital adjustment over time ($b = -.47$, $SE = .15$, $P = .002$). For caregiver perception of life threat and treatment intensity, no main effects or interaction effects were found. Lastly, the variable representing cumulative stress was examined, representing multiple, co-occurring stressors. There was a main effect, such that families with high cumulative stress relative to other families had lower marital adjustment at the end of the first year of treatment ($b = -50.48$, $SE = 22.58$, $P = .03$; see Figure 1), but did not differ in their rate of change in marital adjustment over time.

4 | CONCLUSIONS

This study examined the influence of caregiver perception of 5 stressors on the trajectory of marital adjustment during the first year following diagnosis of pediatric cancer. We found that while average levels of marital adjustment did not change across the year and most couples were in the happily married range at the end of the year, there was substantial variability between families regarding both rates of change and ending points. Thus, the lack of average change was because of differing trajectories between families rather than indicative of stability, and some couples were in the distressed range at the end of the first year of treatment. By using growth models capable of examining variability around an average trajectory, these findings extend previous work and may explain discrepancies in the literature.

Higher average economic strain relative to other families was associated with consistently lower levels of marital adjustment over time, resulting in relatively lower levels of marital adjustment at the end of the first year (see Figure 1). These results concur with previous literature stressing the heavy toll pediatric cancer has on family economics¹⁵ and the impact of economic threat on couples' well-being.⁴⁰ This finding has important implications for predicting levels of marital quality during treatment. Families with low socioeconomic status may be disproportionately affected by the economic burden of cancer treatment,¹⁶ and therefore may be at increased risk for low marital quality.

Families with higher average frequency of treatment events and negative life events declined in marital adjustment over time and had lower marital adjustment at the end of the year. When stressors are occurring frequently, caregivers are likely emotionally and physically taxed, making emotion regulation and effective interactions with their partner more challenging. Over time, this may have an increasingly detrimental effect on the couple's relationship quality. Importantly, these findings indicate that the frequency of treatment-related and negative life events can predict change in marital satisfaction to a considerable degree in both directions. Happily married couples facing frequent Marital adjustment, treatment-related events, general negative events, and economic strain stressors may become distressed, while when stressor frequency is low, happily married couples may show a renewed strengthening of their marital bond over time. Stressor frequency may thus explain differences in trajectories of marital adjustment in other studies.^{7,8,11,13}

Interestingly, treatment intensity and perception of life threat were not related to marital adjustment. These findings suggest that marital adjustment may be more influenced by the frequency of treatment events rather than perceived overall treatment intensity or prognosis. For example, in the face of an overall intensive treatment regimen or perceptions of a poor prognosis, parents may accept or gird themselves against the realities of the required treatments and develop some cohesion as a couple in the face of stressors. However, undergoing frequent treatment procedures (eg, lumbar punctures, chemotherapy), treatment events (eg, long hospital stays, waiting for test results), or dealing with additional negative life events outside their child's cancer (eg, moving, parent losing a job) may function as a "tipping point" leading to a decline in marital quality.

Finally, higher cumulative stress was also associated with consistently lower marital adjustment over time. Couples for whom overall stress was higher had stable lower levels of marital adjustment across time, but their relationship adjustment did not decrease. While frequency of specific negative events may have an increasingly detrimental effect on marital quality, high stress in general may have a consistent but negative effect on the marital relationship over time. Our results support previous research suggesting that the harsh impact of daily hassles is more strongly associated with low health than are major life events.⁴¹

4.1 | Study limitations

This study has several limitations that may be addressed by future studies. First, the current study addressed marital adjustment as a whole. An important direction for future research will be to examine whether stress differentially affects some aspects of the marriage (eg, intimacy). Second, single reporter bias may have influenced results as measurement of a dyadic construct occurred via single-respondent questionnaires. Future work may benefit from using observational assessments of marital relations or including both partners' perceptions. Third, missing data were present in the current study. It is possible that couples with lower marital adjustment or higher levels of stress may have been less likely to complete questionnaires, resulting in underreporting of marital problems. However, the number of completed packets was generally not correlated with marital adjustment or level of stress across the 12 time points. Finally, this study focused on 1 set of predictors relating

to stress. There are undoubtedly other possible predictors of marital adjustment across this significant first year. Potential factors that could be addressed in future studies include personal characteristics of the parents, parental psychopathology, optimism, locus of control, and other subjective aspects of stress (eg, coping resources, stress processing).

4.2 | Clinical implications

The current study has implications for understanding family functioning in times of prolonged stress. Medical personnel should be aware of the effects of economic strain, treatment-related events, and negative life events on marriage to help identify families at higher risk for marital problems during treatment. Utilizing caregiver reports of stress both related to treatment and from outside sources may provide a more useful screening tool than medical data alone.

Couples with considerable stress may benefit from meeting with a hospital counselor to facilitate effective coping skills and communication. It is possible that awareness of the potential for stress to affect their marriage may itself effectively ameliorate conflict. Ultimately, understanding that the daily battle with pediatric cancer extends beyond the individuals to affect the marital relationship is important when offering support to families.

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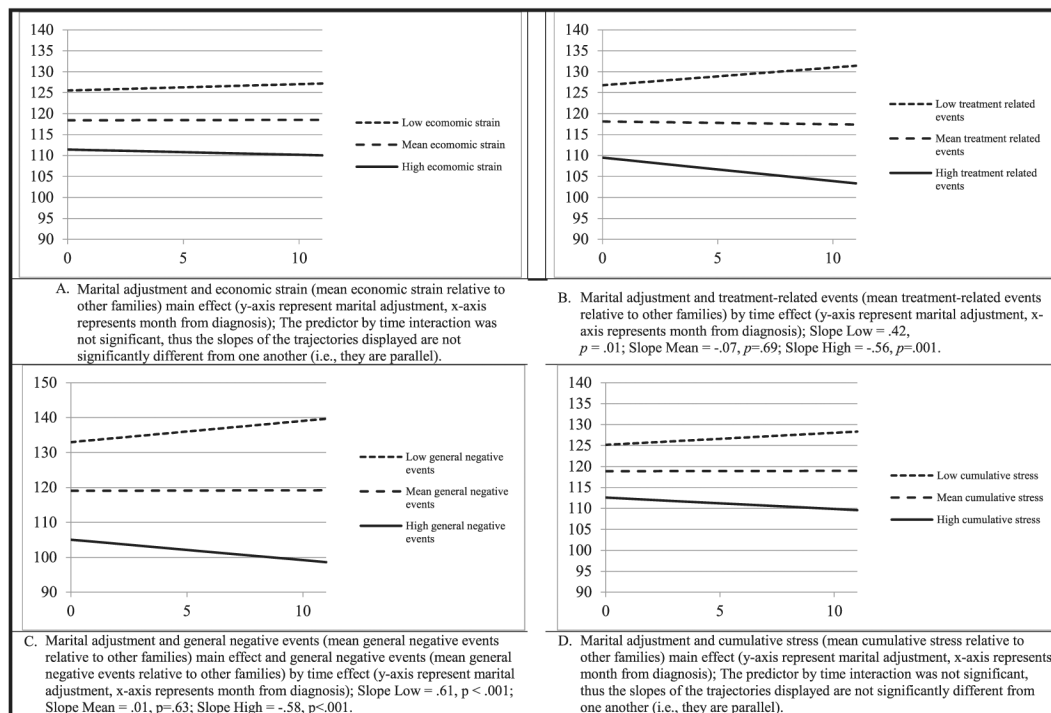
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**FIGURE 1.**

Marital adjustment, treatment-related events, general negative events, and economic strain

TABLE 1

Descriptive information—marital adjustment over the 12 time points

Time (Months)	T1	T2	T3	T4	T5	T6
n	118	7	56	79	79	86
Mean	121.44	129.29	119.20	120.68	123.13	119.30
SD	22.12	12.57	25.08	23.09	22.04	26.07
Minimum	47.00	110.00	54.00	38.00	26.00	45.00
Maximum	163.00	149.00	165.00	163.00	164.00	164.00
Percentage of above cutoff	78.45	100.00	71.43	78.48	80.77	73.26
Time (months)	T7	T8	T9	T10	T11	T12
n	58	58	64	57	55	66
Mean	125.60	125.98	124.53	122.68	126.04	124.30
SD	24.44	22.29	25.74	25.07	21.18	23.51
Minimum	45.00	59.00	16.00	57.00	63.00	66.00
Maximum	165.00	166.00	166.00	166.00	166.00	166.00
Percentage of above cutoff	84.21	82.76	85.71	71.93	85.19	81.54

Participants above cutoff represent high marital adjustment.

Model fit indices and comparisons

TABLE 2

	AIC	BIC	Residual Est. (Delta Variance Explained)	Est. of Random Intercept Var., Sig. (% of Change)	Est. of Random Slope Var., Sig. (% of Change)	-2 RLL	in χ^2 (No. of Parameters)	p
Step 1—unconditional								
Fully fixed	7167.67	7172.33	553.83				7165.67 (2)	
Step 2—random effects								
Random intercept	6322.80	6332.12	110.11 (80.12%)			6318.80	846.87 (3)	<.001
Step 3—fully random								
Random Intercept & Slope	6284.78	6303.42	93.67 (14.93%)	839.15, <.001	1.57, <.001	6267.78	42.02 (4)	<.001
Step 4—predictors								
Random Intercept & Slope								
Economic strain	6286.09	6323.40		780.25 (.07%)	1.52 (.03%)	6270.09	6.69 (6)	0.04
Life threat	6292.33	6324.97		830.45 (.01%)	1.54 (.02%)	6278.33	-1.55 (6)	0.21
Treatment intensity	6294.30	6331.60		832.24 (.01%)	1.54 (.02%)	6278.30	-1.51 (6)	0.47
Treatment-related events	6266.59	6303.88		784.64 (.06%)	1.32 (.16%)	6250.59	26.19 (6)	.0001
General negative events	6268.56	6305.87		635.53 (.24%)	1.18 (.25%)	6252.56	24.22 (6)	.0001

Delta variance explained = delta variance explained in comparison to previous step.

Est., estimate; Var., variance.