



Emotional adjustment among parents of adolescents and young adults with cancer: the influence of social constraints on cognitive processing and fear of recurrence

Emilia E. Mikrut¹ · Aliza A. Panjwani² · Rebecca Cipollina³ · Tracey A. Revenson^{2,4}

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Abstract Parents of adolescents and young adults (AYAs) with cancer experience distress comparable to other caregiver populations, but remain understudied. This study tested the social cognitive processing model of emotional adjustment to cancer. We hypothesized that social constraints on emotional disclosure would inhibit cognitive processing and be related to greater fear of cancer recurrence (FCR), potentially negatively influencing psychological adjustment. Data were collected through an online cross-sectional survey study of 66 parents of AYAs with cancer (aged 15–39) and analyzed using bootstrapping techniques for ordinary least squares regression. One-third of the parents reported moderate to severe depressive symptoms. Serial mediation analyses indicated that greater social constraints were related to poorer cognitive processing and higher FCR, and, ultimately, greater depressive symptoms. Alternative models were tested and were not significant. Future psychosocial interventions for parents of

AYAs with cancer should include improving cancer-related communication between parents and their social network.

Keywords Caregivers · Parents · Cancer · Social constraints · Fear of recurrence · Young adult

Introduction

The diagnosis of cancer is a life-changing event, not only for the individuals diagnosed (Bellizzi et al., 2012), but also for their families (Northouse et al., 2012; Revenson, 2016). Family members' distress levels are often comparable to the patients' (Nelson & Gold, 2012), especially when the caregiver is the parent (Kazak et al., 2004; Klassen et al., 2007). Some evidence suggests that symptoms of distress are more pronounced among parents than their diagnosed children (Juth et al., 2015) and persist even after treatment completion (Kazak et al., 2004). The majority of the research on parents has centered on those caring for a young child with pediatric cancer (Ljungman et al., 2014; Pai et al., 2007) even though compared to children 14 and under, adolescents and young adults (AYAs; aged 15–39) are six times more likely to be diagnosed with cancer (National Cancer Institute, 2018). A recent study assessing recruitment success of AYA survivors of childhood cancer, between the ages of 15 and 25, and their parents demonstrated that the parents were harder to recruit than the AYA children (36.5% vs. 50% response rate, respectively; Hamilton et al., 2018). Moreover, parents of older AYA survivors were the most difficult group to recruit, suggesting that this population of family caregivers may be understudied and therapeutically underserved.

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✉ Aliza A. Panjwani
apanjwani@gradcenter.cuny.edu

- ¹ Department of Psychology, St. John's University, Queens, NY, USA
- ² Department of Psychology, Graduate Center, City University of New York, New York, NY, USA
- ³ Department of Psychology, Rutgers University, New Brunswick, NJ, USA
- ⁴ Department of Psychology, Hunter College City University of New York, HN611 695 Park Avenue, New York, NY 10065, USA

Cancer that occurs in adolescence and young adulthood is “off-time” in the normative adult life cycle, causing disruptions to typical developmental tasks such as completing one’s education or developing intimate relationships (Panjwani et al., 2019a), and can lead to distress (Barnett et al., 2016). Parents of AYAs with cancer report unique challenges, including familial conflict over discrepancies between parental priorities and those of their AYA children; these discrepancies contribute to greater stress for both the patient and parent (Grinyer, 2009). While parents of AYAs have worries about the future (Panjwani & Revenson, 2017), they may also experience a sense of isolation or have difficulty with their concerns being heard or understood.

One study suggested that nearly one-third of parents of AYAs with cancer (aged 15–25) experience depressive symptoms at a clinical level (28%, McCarthy et al., 2016); in another study that included parents of adolescents with cancer (defined as ages 11–19), approximately one in five parents had moderate to severe post-traumatic stress (Alderfer et al., 2005). Understanding the psychosocial factors that contribute to distress among parents of AYAs will help develop psychological interventions that can improve quality of life for the parents, their children, and the family as a whole. Given that the social context affects adjustment to illness, this study examines both intrapersonal and interpersonal variables that may affect distress among parents of AYAs with cancer.

The social cognitive processing model of adjustment

The social cognitive processing model of emotional adjustment to cancer (SCP; Lepore, 2001) posits that individuals coping with their own or a family member’s cancer diagnosis benefit from disclosing negative thoughts, concerns, and feelings to close others. Disclosure aids emotional processing and engages adaptive coping strategies (Smyth et al., 2012). Emotional disclosure improves psychological adjustment, but only when it occurs within a receptive social environment (Lepore & Revenson, 2007). Social interactions that discourage, limit, or modify another person’s expression of thoughts and feelings are known as *social constraints*. Social constraints hinder emotional disclosure and have been related to poorer adjustment to illness among adults with cancer and their caregivers (Adams et al., 2015; Cohee et al., 2017b).

In the face of a negative life event, such as a cancer diagnosis, persistent negative thoughts can occur frequently and automatically (Cordova et al., 1995). The inability to process fears may be one mechanism by which social constraints on disclosure lead to poor adjustment (Cohee et al., 2017a; Lepore, 2001; Sheridan et al., 2010). Meta-analytic findings show that suppression of thoughts

(as opposed to expression or disclosure) leads to a *rebound effect*, wherein not thinking about or processing particular thoughts, such as “what if my child’s cancer recurs”, paradoxically generates more of those same thoughts and greater psychological distress (Abramowitz et al., 2001). Among individuals with cancer and their families, fear of cancer recurrence (FCR) is one such commonly cited intrusive concern (Lebel et al., 2017; Mellon et al., 2007). Family members of people with cancer, including parents, report similar or higher levels of FCR when compared to patients. FCR has emerged as a robust predictor of depressive and anxiety symptoms among cancer caregivers (Mellon et al., 2007).

The current study applies the SCP model to an understudied caregiver population, parents of AYAs with cancer, in order to understand how social constraints may influence psychological distress. We hypothesize a direct relationship between social constraints and distress that is consistent with previous literature (Pasipanodya et al., 2012) as well as a sequential indirect effect. Prior studies among breast cancer patients and/or their partners have shown that the relationships between social constraints and depressive symptoms (Cohee et al., 2017b) or social constraints and FCR (Cohee et al., 2017a) are mediated by cognitive processing. To our knowledge, no study has combined these constructs into one model. Understanding how parent caregivers respond to social constraints on emotional disclosure and delineating a mechanistic pathway for how constraints lead to poorer adjustment is instrumental in developing targeted interventions and improving distress outcomes (Stanton et al., 2013).

Grounded in SCP theory, we propose a model that includes cognitive processing and FCR as sequential mediators of the relationship between social constraints and depressive symptoms. Specifically, we hypothesize that greater social constraints will limit cognitive processing (i.e., lead to greater intrusive thought and cognitive avoidance), which will be associated with greater FCR. Greater FCR, in turn, will be related to more depressive symptoms. As previous work has demonstrated significant relationships between time since diagnosis and distress among patients and caregivers (see meta-analysis by Hodges et al., 2005), it will be included as a covariate in our model (see Fig. 1).

Methods

Participants and recruitment

Parents of AYAs with cancer were recruited through collaboration with Stupid Cancer, a national nonprofit advocacy organization for young adults with cancer, serving

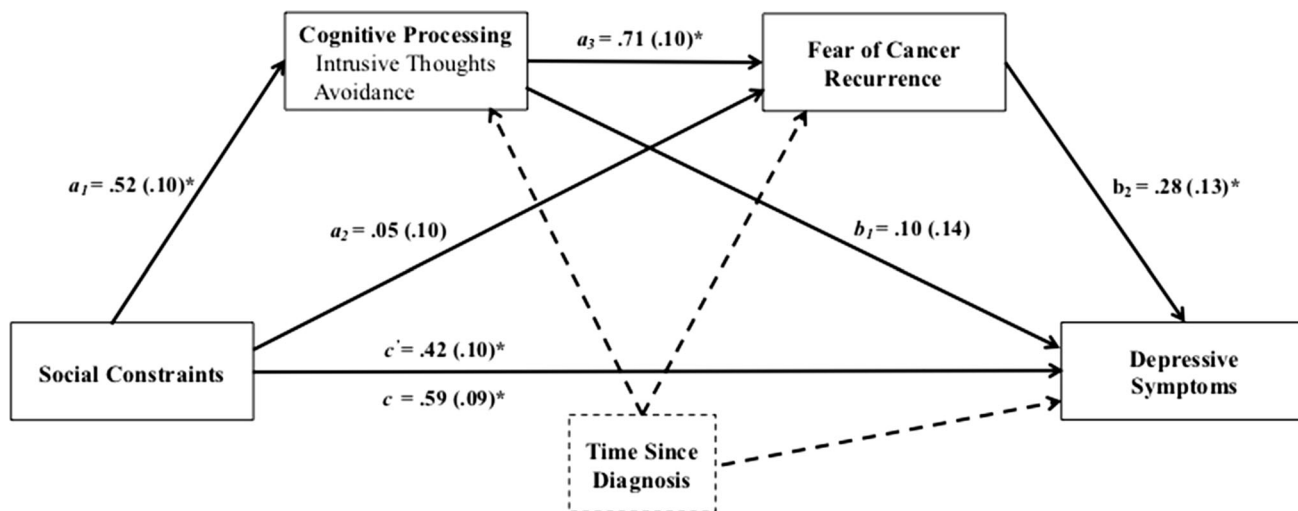


Fig. 1 Serial mediation model controlling for time since diagnosis, showing the influence of social constraints on depressive symptoms, as sequentially mediated by cognitive processing (Mediator 1: higher numbers = lower cognitive processing) and fear of cancer recurrence (Mediator 2: higher numbers = more fear of recurrence). All

coefficients are standardized. Numbers in parentheses indicate standard errors. Asterisks indicate significant coefficients ($*p < .001$). The c path in the model reflects the total effect; the c' path reflects the direct effect

over 300,000 individuals on its social platforms. Stupid Cancer provides information about the emotional, developmental, legal, and financial burden of cancer and organizes events for young adults with cancer. Recruitment for this study was conducted through the organization’s social media pages; the description of the study was brief and directed at both AYAs and their parents. Interested individuals were instructed to click a link for more information.

Eligibility criteria were being a parent of a living AYA with cancer who was currently between the ages of 15 and 39 years old and who had been diagnosed during adolescence or young adulthood (between the ages of 15 and 39). Participants were required to be English speaking and reside in North America. Eighty-seven individuals met eligibility criteria and consented to participate. Of these 87 participants, 21 were removed due to missing or incomplete data on the variables used in these analyses. The study was approved by the appropriate institutional review board.

Procedure

All screening and survey questions were conducted online using Qualtrics software. Participants completed screening questions to assess eligibility. If they met eligibility criteria, they were directed to the informed consent page for the study, which provided a detailed description of the study and their rights as participants. If they provided online consent, they were directed to the questionnaire. Documented consent was saved separately from survey

responses. Respondents received financial remuneration for their time with an e-gift card.

Measures

Participants reported their own demographic information as well as their AYA child’s demographic information. Participants also provided medical information (type of cancer, year of diagnosis, and treatment status [active vs. completed]) for their AYA child’s cancer diagnosis.

Social constraints

Social constraints on disclosure over the past 2 weeks were assessed with the 15-item measure developed by Lepore and Ituarte (1999). Sample items include “How often did a family member or friend minimize your problems?” and “How often did a family member or friend tell you to try not to think about the cancer?” (response scale: 1 = never to 5 = very often). Items were summed, with higher scores indicating greater social constraints ($\alpha = .97$).

Cognitive processing

Cognitive processing over the past 2 weeks was assessed with the revised Impact of Events (IES-R) scale (Weiss & Marmar, 1997). Though the IES-R is designed to assess symptomology of post-traumatic stress disorder, it is commonly used as an indicator of cognitive processing, and well as a mediator of adjustment outcomes, in psycho-oncology research (Cohee et al., 2017b; Sheridan et al.,

2010; Lepore, 2001; You & Lu, 2014). The intrusive thoughts subscale of the IES-R contained eight items, including “I thought about it when I didn’t mean to” in respect to the child’s cancer; the avoidance subscale also contained eight items, including “I tried to remove it from my memory” in respect to the child’s cancer (response format: 0 = not at all to 4 = extremely). As the two subscales were strongly correlated ($r = .74, p < .001$), the 16 items were summed into a single measure ($\alpha = .93$). Higher scores indicate poorer cognitive processing.

Fear of cancer recurrence

The Concerns about Recurrence Scale (Vickberg, 2003), developed for breast cancer survivors, was adapted for parents. Sample items are: “How often do you worry about the possibility that your child’s cancer could recur?” and “How much does the possibility that your child’s cancer could recur upset you?” The five items were answered on a 6-point scale (1 indicating low fear and 6 indicating high fear) and summed, with higher scores indicating higher FCR ($\alpha = .91$).

Depressive symptoms

Depressive symptoms over the past 2 weeks were measured with the 9-item Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001; response format: 0 = not at all to 3 = nearly every day). Items were summed, with higher scores indicating more severe depressive symptoms ($\alpha = .91$).

Data analyses

Serial mediation tested the direct effects of social constraints on depressive symptoms as well as the indirect effects through cognitive processing and FCR. Following recommendations by Hayes (2018), ordinary least squares path analyses were conducted (SPSS Version 23, 2017) using the PROCESS macro (Model 6). This method approximates coefficients using bootstrapping, which does not assume a normal sampling distribution of the indirect effect (ab). As the indirect effect is known to have a non-normal distribution, bootstrapping is preferable and can allow for avoiding power concerns (Edwards & Lambert, 2007; MacKinnon et al., 2004). Variables for the model were standardized. Although our hypothesis that poorer cognitive processing precedes FCR is theoretically grounded (Abramowitz et al., 2001; Lepore, 2001), there may be concern about the sequence of mediators as the data are cross-sectional. Consequently, we also tested whether there would be a sequential indirect effect if FCR preceded

cognitive processing but hypothesized that we would not find such an effect.

Results

Thus, the sample used for analyses consisted of 66 parents of AYAs with cancer (92% mothers). The majority of parents were middle aged ($M = 55.17$ years, $SD = 7.02$) and either married or in a long-term relationship (80%). All were heterosexual and identified as White. Over 70% of the parents earned \$60,000 or above annually. Per inclusion criteria, their children ranged in age from 15 to 39 years old ($M = 27.50$, $SD = 6.34$); two-thirds (66.7%) of the children were female. The most commonly occurring diagnoses were blood cancers (leukemia and lymphoma, 45.5%), brain cancer (12.1%), testicular cancer (10.6%), and gynecological cancer (10.6%). Three-fourths of the AYAs (75.8%) had been diagnosed within the past six years, ($M = 3.44$ years, $SD = 3.89$), with an average age at diagnosis of 23.62 ($SD = 6.29$). Slightly more than one-third (37.9%) of the AYAs were currently in treatment.

Using the standard clinical cut-off score of 10 to delineate individuals with symptoms of depression indicative of a likely clinical diagnosis (Kroenke et al., 2001), one-third (31.8%) of the parents reported moderate to severe depressive symptoms, although there was wide variation ($M = 6.23$, $SD = 6.33$). The continuous measure of depressive symptoms was significantly correlated with greater social constraints, poorer cognitive processing, and greater FCR (Table 1). The relationship between time since diagnosis with FCR ($p = .095$) and depressive symptoms ($p = .06$) approached significance. Table 1 presents the means, standard deviations, and bivariate correlations among the study variables.

Mediation analyses

Serial mediation analysis with 10,000 iterations of bootstrapping (Hayes, 2018), controlling for time since diagnosis, assessed whether cognitive processing and FCR sequentially mediated the influence of social constraints on depressive symptoms and simultaneously tested the two single-mediator pathways. First, the model examined whether the relationship between social constraints and depressive symptoms was mediated by cognitive processing alone. The standardized specific indirect effect for this pathway was not significant ($a_1b_1 = .05$, $SE = .12$; 95% CI = $-.14, .32$). Second, the model tested whether the relationship between social constraints and depressive symptoms was mediated by FCR alone; this standardized indirect effect also was not significant ($a_2b_2 = .01$, $SE = .03$; 95% CI = $-.05, .09$). The serial indirect effect was

Table 1 Descriptive statistics, coefficient alpha, and inter-correlations among variables

	Mean (SD)	Scale range	Observed range	Social constraints	Cognitive processing	FCR	Depressive symptoms
Social constraints	29.74 (14.66)	15–75	15–69				
Cognitive processing	17.61 (13.24)	0–64	0–56	.52*			
Fear of cancer recurrence (FCR)	20.45 (7.18)	5–30	6–30	.42*	.74*		
Depressive symptoms	6.23 (6.33)	0–27	0–27	.60*	.57*	.57*	
Time since diagnosis	3.44 (3.89)	–	0–20	.02	–.20	–.21	–.23

*Denotes significance at $p < .01$

significant ($a_1a_3b_2 = .10$, $SE = .05$; 95% CI: .004, .21), supporting our hypothesis that experiencing more social constraints predicts greater depressive symptoms through the sequential influence of lower cognitive processing and greater FCR. As hypothesized, the direct effect of social constraints on depressive symptoms, removing the influence of the mediators and covariate, was also significant ($c' = .42$, $SE = .10$; 95% CI: .10, .28), suggesting that the mechanistic relationship between social constraints and depressive symptoms is multi-layered. This model accounted for 52% of the variance in depressive symptoms, $R^2 = .52$, $F(4, 61) = 16.30$, $p < .001$. All paths, associated coefficients, and standard errors for this serial mediation model can be found in Fig. 1.

The second alternative serial mediation model tested whether the sequential indirect effect would be significant if FCR preceded cognitive processing. We used the same method and analysis, re-specified with the alternative order, and found no evidence of a serial indirect effect. In other words, we only found evidence for our hypothesized serial indirect effect—in that, cognitive processing precedes FCR. All paths, associated coefficients and standard errors for the second serial mediation model can be found in the Electronic Supplementary Material.

Discussion

This study is the first to empirically evaluate the salience of the SCP model (Lepore, 2001) among parents of AYAs with cancer, a vulnerable and understudied caregiving population. We explored how perceived social constraints on emotional disclosure from friends and family may influence psychological distress among parents, who may be facing unique stressors in coping with their AYA child's cancer (Grinyer, 2009). As hypothesized, we found evidence for a serial indirect effect of social constraints on depressive symptoms through cognitive processing and FCR; importantly, mediation did not occur with cognitive processing or FCR alone. This pattern of findings lends

support for the sequential nature of the mechanistic process underlying the relationship between social constraints and depressive symptoms. Notably, our model explained roughly half of the variation in depressive symptoms among this sample of parents of AYAs with cancer.

The analyses suggest that perceived social constraints inhibit cognitive processing (i.e., lead to more intrusive thoughts and avoidance) which, in turn, is related to greater FCR and, ultimately, greater psychological distress. Previous findings have shown that the prevention of emotional disclosure can lead to avoidance or suppression of distressing thoughts, which paradoxically results in a higher frequency of those thoughts or fears (Wegner et al., 1991) and, subsequently, greater depression (Szasz, 2009). When parents are restricted in speaking openly about their child's cancer, they may be unable to create a narrative to process the psychosocial and medical impact of their child's illness. Instead, they may engage in unhealthy coping strategies, such as rumination or catastrophizing, which can hinder adjustment (Caes et al., 2014).

Also consistent with our hypotheses, there was a direct relationship between social constraints and depressive symptoms, controlling for the influence of mediators, which has been demonstrated in previous studies (Cohee et al., 2017b). The effect of emotional disclosure, or lack thereof, on indices of adjustment is likely complex, with multiple mechanisms operating together to explain the full relationship. For example, among breast cancer patients, perceived stress and negative affect have been cited as mediators explaining the effects of social constraints on sleep quality (Yeung et al., 2017) and quality of life (You & Lu, 2014).

Although patients certainly experience social constraints, the focus of our study was on parents of AYAs diagnosed with cancer, family caregivers who may be difficult to access or recruit (Hamilton et al., 2018). Though less studied than parents of young children with pediatric cancer, rates of depressive symptoms among parents of AYAs with cancer in our sample were comparable to parents with younger children (e.g., Creswell et al.,

2014). Some evidence suggests that distress among parents of AYAs with cancer is linked to the developmental stage of their child with cancer. Qualitative research has documented troubled relationship dynamics between parents and AYA children with cancer, such as the conflict between parents' drive to help and protect and the child's desire to maintain a sense of independence (Grinyer, 2002, 2009). As such, parents of AYAs with cancer may experience some unique concerns and if they perceive social constraints within their close relationships, they may be unable to share or process their worries.

Implications for practice and future research

As parents of AYAs with cancer are understudied and difficult to reach (Hamilton et al., 2018), they may have limited opportunities to gain information and access needed mental health services. Very few evidence-based interventions for family caregivers exist, and the majority that do exist are aimed at improving caregiving skills rather than caregivers' psychological adjustment exclusively (Northouse et al., 2012). Therefore, our data provide a window on points of intervention for this vulnerable caregiving group. As our model was able to account for a substantial portion of reported depressive symptoms, we can expect that providing psychosocial treatments that intervene on the processes delineated in this model would be of clinical significance to parents of AYAs with cancer.

Assessing the experience of social constraints with respect to emotional disclosure should not be overlooked among the parents of AYAs with cancer. Possibly, the supporters of these parent caregivers—close friends, family, and even their own partners—may be offering care that is perceived as unsupportive. They may dismiss the parent's concerns around recurrence, which, in turn, inhibits the parent's opportunities to process fears and distressing emotions. Alderfer et al. (2005) hypothesized that among parents of children with pediatric cancer, parent-dyads in which one partner experiences intrusive thoughts and another experiences cognitive avoidance may be particularly at risk for poor adjustment.

Accordingly, interventions for parent caregivers of AYAs with cancer should include several components. To overcome social constraints, teaching parents how to communicate needs to their spouses and wider support network may be more effective when including both parents of the AYA with cancer and/or inviting a support provider from the parents' network for a session. As well, helping parents appraise controllable and uncontrollable aspects of the illness-related stressor and subsequently utilize appropriately matched coping strategies (e.g., problem-solving, reappraisal, acceptance) may be paramount. Particularly with uncontrollable aspects of illness-

related stressors, emotion regulation skills are an often-missing component in interventions to reduce distress among caregivers of cancer patients (Northouse et al., 2012). Emotion-regulation therapies for family caregivers of cancer patients have previously demonstrated medium to large effect sizes in decreasing symptoms of depression and anxiety (Applebaum et al., 2018). Consequently, mindfulness techniques and a focus on values-based living are intervention components that may address the negative perseverative thinking underlying the distress experienced by parents (Mehranfar et al., 2012; Panjwani et al., 2019b), promoting distress tolerance and acceptance of intrusive thoughts rather than avoidance. Meta-analytic findings from research on cancer patients provide further support that emotion regulation techniques lessen symptoms of distress (Piet et al., 2012), potentially through the reduction of cognitive avoidance (Bränström et al., 2010) and FCR (Luberto et al., 2019).

Limitations

Parents of AYAs with cancer become increasingly difficult to recruit as the age of the child increases (Hamilton et al., 2018) and yet parents often assume caregiving responsibilities for their adult children when they become ill. Although Internet recruitment is a cost-effective and efficacious tool to engage hard-to-reach populations such as informal caregivers (Horrell et al., 2015), concerns about selection bias should be noted. Our sample was fairly homogenous—predominantly white, female, and of high socioeconomic status. Given that recruitment necessitated some form of contact with Stupid Cancer, a national advocacy organization for AYAs with cancer, the parents included in this study may be better connected than other parents of AYAs with cancer. Though this may restrict the generalizability of our findings, it suggests that even among potentially connected parent caregivers, the experience of social constraints is a salient issue affecting psychological adjustment.

The cross-sectional design limits our ability to draw definitive, predictive conclusions about causality. To that end, we tested an alternative serial mediation model, which did not reach significance, lending support to our proposed order of mediators. While one suggestion may be to conduct these analyses using a longitudinal design, those data, unless experimental, are also subject to their own limitations with respect to causality (Hayes, 2018; Salthouse, 2011). With this in mind, we offer that our mediation analyses provide more information than simple inter-correlations among variables. Future work with more diverse samples is necessary to replicate and expand these findings among parents of AYAs and other understudied caregiver populations.

Conclusion

This study draws on the social cognitive processing theory of emotional adjustment to cancer (Lepore, 2001) to understand how one aspect of the social context—social constraints—affects the well-being of parents of AYAs with cancer. Our findings suggest a process by which social constraints inhibit cognitive processing of the situation, thereby increasing fear of recurrence and psychological distress. Social relationships are important for parents' adaptation to this severe stressor, but as shown with studies of cancer patients and survivors, not all aspects of social relationships enhance adjustment.

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Compliance with ethical standards

Conflict of interest Emilia E. Mikrut, Aliza A. Panjwani, Rebecca Cipollina and Tracey A. Revenson declare that they have no conflict of interest.

Human and animal rights and Informed consent All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors. Informed consent was obtained from all individual participants included in the study.

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