Thought Intrusion Among Adults Living With Complex Regional Pain Syndrome

Jessica A. Lohnberg
VA Palo Alto Health Care System, Palo Alto, California

Elizabeth M. Altmaier
University of Iowa

Purpose: This study investigated the presence and influence of intrusive thoughts among adults previously diagnosed with complex regional pain syndrome. Method: The present study used an Internet-based survey completed by a sample (N = 326) from two national organizations. Results: After controlling for age, gender, and pain level, intrusive thoughts were significantly related to disability and health-related quality of life. Conclusions/Implications: Intrusive thoughts about the inciting event that caused CRPS uniquely influenced pain and quality of life, suggesting a potential mechanism to target for intervention. Understanding factors that relate to maintenance of CRPS and its resulting disability will help in the development of treatments to improve quality of life.

Keywords: chronic pain, complex regional pain syndrome, cognitions, quality of life

Impact

• Complex regional pain syndrome (CRPS) is a painful condition often resulting from a relatively benign injury event and yet frequently leads to significant physical disability and impaired quality of life. Little is known about what factors predict this impairment; this study is the first to examine the role of intrusive thoughts related to the inciting event that caused CRPS in physical disability and quality of life among individuals living with CRPS.
• This study confirms that intrusive thoughts uniquely influenced pain and quality of life.
• Results of this study suggest that intrusive thoughts may be a modifiable target for intervention to influence the onset, maintenance, or exacerbation of physical disability and impaired quality of life in patients with CRPS.

Introduction

Complex regional pain syndrome (CRPS) is a chronic pain condition that develops following a seemingly innocuous injury or incident, such as fracture, soft tissue damage, low-grade infection, and frostbite, or after stroke or myocardial infarction (Baron, Levine, & Fields, 1999). This condition, first described during the American Civil War, has a complex history characterized by multiple name changes at-
fining the event as less problematic than first appeared. Returning to the example, a parent who loses a child may perceive himself or herself as “stronger than I had thought” or as having increased empathy for others’ grief and “making me a better person.”

However, for some persons, rumination becomes intrusive, when thoughts about the event and its aftermath are unwanted and uncontrollable. These intrusive thoughts have been identified as a barrier to adjustment in a variety of chronic conditions. For example, an extensive longitudinal study (Dupont, Bower, Stanton, & Ganz, 2013) of breast cancer survivors revealed that a greater presence of intrusive thoughts at the baseline assessment was associated with increased negative behaviors at the same time and at a 1-year follow up. These negative behaviors included physical symptoms, such as fatigue and depression, and poor health-related quality of life.

Similar findings concerning the deleterious impact of intrusive thoughts on recovery have been noted in studies of persons with pain conditions (Soo, Burney, & Basten, 2009; Yoshida et al., 2012). For example, rumination leads to intensification of physical symptoms, and an interpretation of the pain as itself uncontrollable and unpredictable. Further, frequent unwanted thoughts can lead to catastrophizing; Casey, Greenberg, Nicasio, Harpin, and Hubbard (2008) documented that transition from acute to chronic pain is accompanied by catastrophizing about the permanence of the pain condition. Similarly, Esteve, Ramirez-Maestre, and Lopez-Martinez (2007) documented that catastrophic thinking predicted ongoing physical disability among persons with chronic pain while acceptance of pain was associated with improved functional status. One possible explanation for the relationship between thoughts and functional status is described by the fear-avoidance model of pain disability (Lethem, Slade, Troup, & Bentley, 1983). In this model, fear of pain leads to avoidance of physical activity that has the perceived potential to exacerbate pain. Over time, continued avoidance of physical activity leads to deconditioning and subsequent disability.

Therefore, the purpose of this study was to examine intrusive thoughts about the inciting event among persons living with CRPS. The goal of the study was to determine if thought intrusion was present among CRPS patients, and if present, negatively influenced pain, disability, and health-related quality of life. Given previous research, our expectations were that intrusive thoughts would be positively related to pain and to disability; we further expected that intrusive thoughts about the inciting event among persons living with CRPS.

The goal of the study was to determine if intrusive thoughts were present among CRPS patients, and if present, negatively influenced pain, disability, and health-related quality of life. Given previous research, we expected that intrusive thoughts would be positively related to pain and disability; we further expected that intrusive thoughts would uniquely predict impaired health-related quality of life.

**Method**

**Participants**

Adults over the age of 18 previously diagnosed with CRPS were recruited via e-mail lists managed by the Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) and the Promoting Awareness of RSD/CRPS in Canada (PARC). To be eligible to participate in this study, participants had to meet the following criteria: (a) be at least 18 years of age; (b) have the ability to read and write for the online survey; (c) self-report as having been diagnosed with CRPS (Type I or Type II) by a physician; (d) meets, or at one time met, IASP criteria for CRPS based on self-reported symptoms; and (e) report no other comorbid chronic pain conditions.

**Procedure**

Participants were recruited via an e-mail sent to subscribers that contained a link to the online survey. Potential participants read information that pertained to informed consent. If they agreed, they were forwarded to the next page. Participants were then asked questions related to the inclusion criteria and were directed to the online survey if they met eligibility requirements. If members were not eligible, they were told that they did not meet inclusion criteria and were thanked for their interest.

**Measures**

**Demographic information.** Demographic information was collected from each participant: age, gender, marital status, employment status, disability status, date of diagnosis, and comorbid conditions.

**Pain.** The short form of the McGill Pain Questionnaire (SF-MPQ; Melzack, 1987) was used to measure pain. It consists of 15 word descriptors that form the Pain Rating Index (PRI): 11 sensory words and four affective words. Examples of word descriptors include throbbing and punishing-cruel. Each word is ranked on an intensity scale from 0 (none) to 3 (severe). Scores range from 0 to 45, with higher scores indicating greater endorsement of severe pain. Coefficient alpha for our study was .87. Test–retest reliability assessed one to three days apart was .75 and .93 among patients with musculoskeletal pain and rheumatic pain, respectively (Strand, Ljunggren, Bogen, Ask, & Johnsen, 2008).

**Intrusion.** The Impact of Event Scale–Revised (IES-R; Weiss & Marmar, 1997) was used to measure thought intrusion. The Intrusion subscale consists of seven items that assess experiences within the past 7 days on a scale that ranges from 0 (not at all) to 4 (extremely), with higher scores indicating greater intrusion. Sample items include “pictures about it popped into my mind” and “I thought about it when I didn’t mean to.” For this study, participants were asked to respond to this questionnaire according to thoughts based on the injury/inciting incident related to CRPS. Scores can range from 0 to 28; coefficient alpha for our study was .91.

**Disability.** The Oswestry Low Back Pain Disability Questionnaire (ODQ; Fairbank, Couper, Davies, & O’Brien, 1980) was used to measure disability. The ODQ contains 10 questions about pain intensity, personal care, lifting, walking, sitting, standing, sleeping, sex life, social life, and traveling. Each question has six response options that range from no limitation to extreme limitation with regard to each activity. Scores are calculated to reflect a percentage of disability, and higher scores reflect greater disability. Instructions were modified to ask participants to rate how pain, instead of low back pain, affects each area of functioning. Coefficient alpha was .87.

**Quality of life.** The Medical Outcomes Study Short-Form Health Survey (SF-36; Ware & Kosinski, 2001; Ware & Sherbourne, 1992) was used to assess quality of life in physical and mental health domains. Participants respond to items with their perception of their experience during the previous 4 weeks; an example is “How much did pain interfere with your normal work (including both work outside the home and housework)?” There are two summary scores: the Physical Component Summary (PCS) assesses bodily pain, limitations due to physical problems, health perceptions, and physical function; the Mental Component Summary (MCS) assesses depres-
sion and anxiety, psychological well-being, and role limitations due to psychological concerns. Each subscale score is transformed to a 0- to 100-point scale; higher scores indicate better physical or mental health. In our study, coefficient alpha was .89 for PCS and .91 for MCS.

Results
A total of 435 participants accessed and completed the online survey. Three persons were excluded because they had not been diagnosed with CRPS and an additional 33 were excluded because of a co-occurring pain disorder. Seventy-three participants were missing at least 10% of the items on at least one of the measures and thus were eliminated from subsequent analyses. The demographic characteristics of this group were compared with the group that was retained with no significant differences noted. For the participants who had less than 10% of the items missing on a measure, mean imputation was conducted. The survey host completed additional validity checks, including examination of duplicate Internet Protocol (IP) addresses; these checks revealed no problems with the completed surveys.

Of the 326 participants included in the analyses, 85.9% were female. There were 280 females and 45 males; one participant did not indicate gender. The ratio of females to males is similar to other reports of gender ratios among patients with CRPS (e.g., de Mos et al., 2007). The sample was approximately 46 years old (M = 46.18, SD = 10.8), mostly Caucasian (91%) and married (59%), and the majority (81.1%) reported some college education or a college degree. Most participants (55.5%) reported disability-related income as their only source of financial support. The mean time since diagnosis was approximately 6 years (M = 5.88, SD = 4.97). Individuals with CRPS Type I (n = 207) and CRPS Type II (n = 49) participated in this study (70 participants reported having been diagnosed with both types). A multivariate analysis of variance revealed no significant differences between participants with Type I versus Type II on any study variables.

The descriptive findings demonstrated that persons in this study were experiencing significant pain and poor quality of life. Participants in this study reported greater pain (M = 31.09, SD = 8.77) than persons with chronic musculoskeletal conditions (Melzack, 1987). Quality of life was also significantly impaired in the study population compared with normative data; both summary scores (PCS: M = 29.43, SD = 8.66 and MCS: M = 39.02, SD = 13.45) were several standard deviations lower than normal population values. When contrasted to a back pain/sciatica population (Ware & Kosinski, 2001), the current study sample had significantly lower scores for both physical and mental health.

The primary purpose of this study was to investigate the experience of intrusive thoughts and their relation to pain, disability, and quality of life among persons with CRPS. Intrusive thoughts were significantly correlated with self-reported pain, r = .38, p < .001. To address the degree to which intrusive thoughts predicted disability and quality of life controlling for pain, three hierarchical regression analyses were conducted. For each regression, age and gender were entered in the first step. Level of pain was entered in the second step, and intrusive thoughts were entered into the third step. To correct for inflated alpha, a Bonferroni correction was used; the .05/3 = .016 required p value for significance.

Thought intrusion significantly predicted disability after controlling for age, gender, and pain: In the full model, pain and thought intrusion were each significant predictors. With all variables in the model, 35% of the variance in disability was accounted for. Physical health quality of life was also predicted by the full model of pain and thought intrusion; 18% of the variance in PCS scores was explained. In a parallel fashion, mental health quality of life was significantly predicted by the full model of pain and thought intrusion; greater endorsement of thought intrusion uniquely accounted for 21% of the variance in MCS scores above and beyond level of pain. Table 1 contains regression values.

Discussion
The purpose of this study was to consider the presence and influence of intrusive thoughts among a population of adults living with CRPS. The sample reported significant limitations in physical functioning and a high incidence of disability-related financial support. Because CRPS is associated with impaired daily functioning and reduced ability to engage in gainful employment, rehabilitative efforts with this population are especially important.

Findings revealed that participants reported a high degree of thought intrusion which was significantly related to self-reported pain. Interesting, thought intrusion was not related to demographic variables of age and gender. There is research (see Robichaud, Dugas, & Conway, 2003) that posits that attempted thought suppression is the primary contribution to gender differences in worry, and therefore it could have been expected that intrusive thoughts would reveal gender differences.

Findings also demonstrated that participants were experiencing high levels of pain and disability and impaired physical and psychosocial quality of life. Most important, thought intrusion was significantly related to disability and health-related quality of life, accounting for a significant amount of variability in study variables after controlling for age, gender, and reported pain levels. These results provide support to models of cognitive processing of events, and to the deleterious effects of thought intrusion in adjustment.

In this study, thought intrusion was related to both physical and psychosocial measures. The mechanisms of this relationship are uncertain, but several pathways can be posited. First, the catastrophic nature of thoughts has been shown to be correlated with symptom exacerbation including pain (Esteve et al., 2007; Jacobsen, Andrykowski, & Thors, 2004). That exacerbation, in turn, would contribute to increased perceptions of the increasing likelihood of pain permanence. Second, research related to the challenge posed to adjustment after a highly stressful event (Park & Gutierrez, 2013) suggests that the disruptions of such core beliefs as “the world is good and safe” are unique predictors to impaired well-being after trauma. Last, the fear-avoidance model of pain (Lethem et al., 1983) suggests that individuals experiencing fear of pain tend to avoid activity that can be perceived to potentially exacerbate pain. Although not formally assessed, intrusive thoughts about the incident causing CRPS likely could have resulted in fear that promoted avoidance of physical activity.

Strengths of this study include the large sample size, particularly because much research on CRPS has focused on participants obtained from a single clinic, and the extended time in which the participants have been living with CRPS. Limitations include the participants being obtained from associations providing online support and resources for individuals suffering with CRPS. Those most likely to
Hierarchical Regression Analysis of Intrusive Thoughts Predicting Disability, Physical Quality of Life, and Mental Health Quality of Life

Table 1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Oswestry Physical Quality of Life</th>
<th>Mental Health Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Physical Quality of Life</td>
<td>Mental Health Quality of Life</td>
</tr>
<tr>
<td>Step 1</td>
<td>$B$</td>
<td>$SE$</td>
</tr>
<tr>
<td></td>
<td>$0.006$</td>
<td>$1.02$</td>
</tr>
<tr>
<td>Age</td>
<td>$0.067$</td>
<td>$2.15$</td>
</tr>
<tr>
<td>Gender</td>
<td>$-0.046$</td>
<td>$2.62$</td>
</tr>
<tr>
<td>Pain</td>
<td>$0.024$</td>
<td>$1.26$</td>
</tr>
<tr>
<td>Intrusive Thoughts</td>
<td>$0.194$</td>
<td>$0.479$</td>
</tr>
</tbody>
</table>

Note: SF-MPQ = Short-Form of the McGill Pain Questionnaire; SF-36 = Medical Outcomes Study Short-Form Health Survey; IES-R = Impact of Event Scale-Revised.

Conclusions

This study is among the first to document the extent and negative influence of intrusive thoughts among persons who have been diag-
nosed with CRPS, a debilitating and chronic pain condition. The negative influence of thought intrusion on physical disability and health related quality of life was demonstrated controlling for the influence of age, gender, and reported pain. The contribution of these findings calls for additional investigation into cognitive components of both chronic pain in general, and CRPS in particular. Both the content of thoughts and an individual’s relationship to them can be successfully altered, and such interventions should be investigated within this patient group.

References


Received October 16, 2012

Revision received August 20, 2013

Accepted August 20, 2013