Distress in Spouse of Prostate Cancer Patient: Relationship between Social Constraints, Avoidance, and Intrusive Thoughts

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Abstract – English
There is a growing body of literature indicating that family caregivers of cancer patients have high levels of distress and might even be more distressed than the patients. Little is known about factors that might contribute to distress among caregivers but in order to design effective interventions it is critical to identify these factors. Guided by the social processing model (SCP) the present study examined if social constraints on emotional expression about cancer would be associated with higher levels of general distress and intrusive thoughts about the cancer. Forty-two spouses of men with prostate cancer participated completed several questionnaires at one time-point. The results revealed that the spouses had significantly higher levels of intrusive thoughts about cancer and general distress, and they perceived higher levels of social constraints. Among the spouses social constraints were positively related to intrusive thoughts about cancer and this relationship was partially mediated by avoidance of cancer related issues and concerns. Social constraints were also negatively related to general distress but this relationship was not mediated by avoidance. The results suggest that intervention aimed at lowering social constraints in expressing emotions among cancer patients may be effective in lowering distress and improving quality of life among caregivers of cancer patient.

Abstract – Icelandic
Distress in Spouse of Prostate Cancer Patient: Relationship between Social Constraints, Avoidance, and Intrusive Thoughts

Cancer is a complex group of diseases with many possible causes, and is one of the most frequently diagnosed illnesses in the world. In the United States alone, more than one million people are diagnosed with cancer every year (American Cancer Society, 2013). It is well established that cancer patients suffer psychological distress concerning the cancer diagnoses (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001; Kaasa et al., 1993). It is also recognized that long-term illness patients, like cancer patients, are mostly taken care of at home by a family member, thus, approximately 65.7 million family caregivers are in the United States alone and about 66% of them are females (National Alliance for Caregiving, 2013). There is a growing body of literature signifying that family caregivers of a cancer patients have high levels of distress and might even be more distressed than the patients (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Mellon, Northouse, & Weiss, 2006; Resendes & McCorkle, 2006). For example, 76% of spouse caregivers in Cliff & Macdonagh (2001) study reported some levels of distress compared to 47% of the prostate cancer patients, 30% of the caregivers experienced severe distress compared to 11% of the patients. However, Merckaert et al. (2012) reported that about 60% of cancer patients experienced moderate to high levels of distress compare to 54 % of the caregivers.

Little is known about factors that contribute to distress among caregivers but understanding these factors are critical for developing effective interventions. One factor that might contribute to their distress is emotional expression but according to the social cognitive processing model it is important for individuals to be able to express their feelings and talk openly about their stress-related thoughts to diminish the probability of distress. Unfortunately,
not everyone has the social network they need when facing a negative life event. One reason could be that caregivers devote enormous amount of time caring for their sick loved one, which in turn decreases their time for social interaction (Enright, 1991; van Ryn et al, 2011). Another reason might be that they perceive social constraints or that important others are not ready or able to listen to their concerns (Eton, Lepore & Helgeson 2005; Major & Gramzow, 1999). For example, Eton et al (2005) found that high social constraints from patients was associated with higher general and cancer-specific distress in a sample of spouses of prostate cancer patients.

According to the social processing model, individuals may try to avoid their thoughts and feelings about a life stressor when they perceive social constraints on emotional expression from the environment (Lepore & Helgeson, 1998). However, avoidance can increase the availability of negative thoughts (Gold & Wegner, 1995), and hinder the processing of stressful events and emotional recovery (Lepore, Cohen Silver, Wortman & Waymerit, 1996; Tait and Silver, 1989).

The literature indicates that avoidance mediates the relation between social constraints and psychological distress. For example, results from a study conducted by Schnur, Valdimarsdottir, Montgomery, Nevid and Bovbjerg (2004) showed that avoidance, measured with Impact of Events Scale (IES), mediated the relation between social constraints and both cancer-specific and general distress in women with family histories of breast cancer.

The above literature suggests that caregivers of cancer patients experience high levels of distress and that social constraints on emotional expression may lead to higher levels of distress, which is mediated by higher levels of avoidance of cancer related concerns. However, the studies are sparse and a majority of previous work has focused on breast cancer. In addition, only one study has directly examined the possibility that avoidance mediates the relationship between social constraints and distress. To address these limitations the present study will examine
spouses of prostate cancer patients, but prostate cancer is the most common cancer among men and the second leading cause of cancer death today (American Cancer Society, 2013), and is one third of all recently diagnosed cancers in Iceland (Krabbameinsskrá, 2012).

Based on foregoing research the following hypotheses were investigated: (a) spouses of prostate cancer patients will report higher level of distress than the patients; (b) higher levels of social constraints from spouse on emotional expression will be related to higher levels of intrusive thoughts and general distress among the spouses; (c) avoidance will mediate the relation between social constraints from spouse and both intrusive thoughts and general distress.

Method

This study was part of a randomized clinical trial that examined the possible level of distress men diagnosed with prostate cancer could have on their spouses.

Participants

The participants were spouses of men diagnosed with prostate cancer. A total of 84 women were offered to participate in the study, of whom 39 declined participation and three had died. The remaining 42 women (50%) were 42-84 years old, with mean age of 65 years (SD=9.06), and were permanently living in Iceland. To be eligible for this research each participant had to be a partner of prostate cancer patient who had participated in a larger ongoing study examining the impact of expressive writing on quality of life. These women had to be able to provide an informed consent and to be able to read and write Icelandic. All the participants volunteered to take part in this research without getting compensation.
Procedure

A letter was mailed to prostate cancer patients who were participating in an ongoing research. The patients were asked to give an envelope including an information letter, consent form and a self-report questionnaire to their spouses who returned the requested information in a pre-stamped envelope. The spouses that did not respond were followed up with a phone call.

Measures

This study is a cross sectional study and all the participants were asked to complete three questionnaires: Hospital Anxiety and Depression Scale (HADS), The Impact of Event Scale (IES) and Social Constraints Scale (SCS).

Demographic questionnaire

The subjects completed standard questionnaire containing seven questions: date, age, where they live, their occupation, education and citizenship, using self-report format.

General Distress

Hospital Anxiety and Depression Scale (HADS) was administered (Zigmond & Snaith, 1983) in the Icelandic version translated by Högni Óskarsson (Schaaber, Smari & Oskarsson, 1990). HADS was used to measure general level of psychological distress in participants’ for the past week. HADS contained 14 questions, seven of them measure depression (e.g., “I’m happy”, ”I have lost interest in may appearance”), and seven of them measure anxiety (e.g., “I get a sort of frightened feeling as if something bad is about to happen”, ”I can sit at ease and feel relaxed”). Participants were asked to rate their feeling on a four-point Likert scale from 0 (never) to 3
(always). Mean score was calculated for the subscales, with a possible range of 0-3 hence, higher scores signified greater levels of anxiety or depression. HADS has been verified to be a reliable and valid measure of both anxiety and depression, with the internal consistency varying between .68 and .93 for anxiety and from .67 to .90 for depression (Bjelland, Dahl, Haug & Neckelmann, 2002). The internal consistency for anxiety was $\alpha=.84$ and for depression $\alpha=.81$. The internal consistency for HADS combined (i.e., general distress) was $\alpha=.89$.

**Avoidance**

To measuring avoidance the Icelandic version of the Impact of Event Scale-Revised (IES-R) was used (Christianson & Marren, 2008) that was translated by Sjöfn Ágústsdóttir and translated back to English by Jakob Smári. IES-R measures avoidance related to specific stressor, in the previous study the stressor was partner’s prostate cancer diagnosis. Eight questions from IES-R scale where used to measure sign of avoidance (e.g., “I was aware that I still had a lot of feelings about it, but I didn’t deal with them”). Mean score was computed for the subscale, with a possible range of 0-4. Cronbach’s alpha for avoidance was $\alpha=.89$.

**Intrusive Thoughts**

To measure intrusive thoughts the Icelandic version of the Impact of Event Scale-Revised (IES-R) was used (Christianson & Marren, 2008) that was translated by Sjöfn Ágústsdóttir and translated back to English by Jakob Smári. IES-R measures intrusive thoughts related to specific stressor, in this case the stressor was partner’s prostate cancer diagnosis. Eight questions were used to measure sign of intrusive thoughts (e.g., “Any reminder brought back feelings about it”).
Mean score was calculated for the subscale, with a possible range of 0-4. Cronbach’s alpha for intrusive thoughts $\alpha=.88$.

**Social Constraints**

The Social Constraints Scale (SCS) (Lepore, 1996) is design to measure the level of social constraints from spouse or partner and from friends or family members. In present study the seven questions that measure social constraints from spouse were used (e.g., “How often did you feel as though you had to keep your feelings about the cancer to yourself because it made him feel uncomfortable?”). Subjects were asked to indicate how often they felt constrained in discussing their feelings toward the cancer, using the Icelandic version that was translated by Áslaug Kristinsdóttir, and translated back to English by Jakob Smári. Participants rate each item on a 4-point Likert scale regarding social constraint they experienced particularly associated to the prostate cancer during the past week. Elevated scores depicted an increase in social constraint from the spouse. The mean score for the both subscales was measured from 1 to 4: 1 (never) to 4 (always). The internal consistency for the present study was $\alpha=.76$ for spouse or partner.

**Design**

This was a cross sectional study of spouses of prostate cancer patients. In testing the main hypothesis, two outcomes variable (intrusive thoughts and general distress), one predictor variable (social constraints from spouse), and one mediator variable (avoidance) were used.
Data Analyses

To analyze the data regression and One-way ANOVA on a software package, SPSS 19, were used. One-way ANOVA was used to examine the psychological difference between genders. Simple regression analysis was used to determine whether social constraints from spouse were related to intrusive thoughts and general distress and multiple regressions were used to examine if voidance would mediate the relation between social constraints from spouse and both intrusive thoughts and general distress (Baron & Kenny, 1986).

Results

Sample Characteristics

Demographic characteristics of participants are shown in Table 1. The participants were from 42-84 years of age, with mean age of 65 years ($SD=9.06$). About 31% of the participant had college education and 38.1% were on the employment market.

Table 1. Sample characteristics

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Frequency (percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>$\geq$ 50 years old</td>
<td>2 (4.8%)</td>
</tr>
<tr>
<td>51-60 years old</td>
<td>8 (19.1%)</td>
</tr>
<tr>
<td>61-70 years old</td>
<td>13 (31.1%)</td>
</tr>
<tr>
<td>$\leq$ 71 years old</td>
<td>10 (23.9%)</td>
</tr>
<tr>
<td>Did not reveal their age</td>
<td>9 (21.4%)</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>16 (38.1%)</td>
</tr>
<tr>
<td>Retired</td>
<td>16 (38.1%)</td>
</tr>
<tr>
<td>Other</td>
<td>10 (23.8%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
</tbody>
</table>
**Statistical Analysis**

Before the hypotheses were tested, analyses were conducted to define if any of the demographic variables were connected to the primary study variables (i.e., intrusive thoughts, avoidance and social constraints from spouse) but none were significant (p’s > .10). In addition, time since cancer diagnose was not related to the main outcome variables.

The first aim of this study was to determine whether spouses of prostate cancer patients were more distressed than the patients. One-way ANOVA yielded significant differences between genders for intrusive thoughts, social constraints from a spouse, anxiety and general distress. As illustrated in Table 2, spouses experienced more intrusive thoughts (p<.05) than their ill husbands, more social constraints from them (p<.01), and they experienced greater general distress (p<.05). When general distress was examined separately for depression and anxiety only anxiety was significantly different (p<.05) with the spouses being more anxious than the patients.

**Table 2. The difference in score between the genders**

<table>
<thead>
<tr>
<th></th>
<th>Women (n = 42)</th>
<th></th>
<th>Men (n = 42)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Mean</strong></td>
<td><strong>Std. Deviation</strong></td>
<td><strong>Mean</strong></td>
<td><strong>Std. Deviation</strong></td>
</tr>
<tr>
<td>Intrusive thoughts- IES</td>
<td>0.69*</td>
<td>0.55</td>
<td>0.42*</td>
<td>0.48</td>
</tr>
<tr>
<td>Avoidance- IES</td>
<td>0.70</td>
<td>0.68</td>
<td>0.52</td>
<td>0.70</td>
</tr>
<tr>
<td>Social constraints from spouse- SCS</td>
<td>1.48**</td>
<td>0.49</td>
<td>1.23**</td>
<td>0.31</td>
</tr>
<tr>
<td>Anxiety- HADS</td>
<td>0.46**</td>
<td>0.42</td>
<td>0.25**</td>
<td>0.27</td>
</tr>
<tr>
<td>Depression- HADS</td>
<td>0.32</td>
<td>0.35</td>
<td>0.22</td>
<td>0.26</td>
</tr>
<tr>
<td>General distress- HADS</td>
<td>0.78*</td>
<td>0.72</td>
<td>0.47*</td>
<td>0.48</td>
</tr>
</tbody>
</table>

*p<0.05; **p<0.01
The second aim of this study was to examine whether social constraints from spouses were related to intrusive thoughts and general distress among participants. Constraints from spouses were positively related to intrusive thoughts, $R^2 = .13$, $F(5, 82), p = .02$, accounting for 13% of the variance in intrusive thoughts. Social constraints was also associated with general distress $R^2 = .40$, $F(26, 56), p < .01$, accounts for 40% of the variance. The third aim was to examine if avoidance mediated the relationship between social constraints and intrusive thoughts and general distress. Before examining the mediation hypothesis it first had to be established that social constraints was related to avoidance and that avoidance was related to intrusive thoughts and general distress. As shown in Figure 1 the results revealed that there was a significant positive relationship between social constraints and avoidance ($\beta = .55, p < .01$) and there was a significant positive relationship between avoidance and intrusive thoughts ($\beta = .75, p < .01$). Testing for the mediation showed that the relationship between social constrains and distress was no longer significant when avoidance was entered into the model ($\beta = .08, p = .58$), as exemplified in Figure 1. This suggests that avoidance mediated the relation between social constraints from spouse and intrusive thoughts.
Figure 1. Social Cognitive Processing Model shows the connection between social constraints, avoidance and cancer-specific distress.

For general distress the results showed that there was a significant association between avoidance and general distress ($\beta = .58, p < .01$). But, as shown in Figure 2, when avoidance was entered into the model to test for mediation the relationship between social constraints and general distress remained significant ($\beta = .45, p < .01$). Thus, avoidance did not mediate the relation between social constraints from spouse and general distress. Separate analyses were conducted for depression and anxiety and the results yield similar outcome as general distress.

![Diagram](attachment:distress_in_spouse.png)

Figure 2. Social Cognitive Processing Model shows the connection between social constraints, avoidance and general distress.

**Discussion**

The main purpose of the present study was to a) examine whether spouses of prostate cancer patients were more distressed than the patient, b) if higher levels of social constraints from the partner were related to higher levels of intrusive thoughts about the cancer and general distress
among the spouses, and c) to determine if avoidance would mediate the relation between social constraints and both intrusive thoughts and general distress. The results supported the hypotheses that the spouses were more distressed than the cancer patient, that social constraints were related to intrusive thoughts and avoidance mediated this relationship. Social constraints were also related to general distress but the relationship was not mediated by avoidance.

The finding, that spouses of prostate cancer patients would be more distressed than the patients is consistent with prior studies that have found that caregivers are more distressed than patients (Mellon et al, 2006; Resendes & McCorkle, 2006). For example, Braun et al. (2007) found that about 40% of caregivers of cancer patients reported significant symptoms of depression compared with 23% of the patients. However, Merckaert et al. (2012) reported that cancer patients experienced more distress than caregivers, and Kim et al. (2008) came to yet another conclusion, whereas their results show that there was no significant difference in psychological distress between survivors of prostate and breast cancer and their spouses. There could be several reasons for these discrepant findings, such as different measures used to assess distress, different types of cancer, gender of the caregiver and variability in sample size. For example, majority or 76% of the participants in Braun et al’s (2007) were females whereas only 50% of the participants in Kim et al’s (2008) study were females. Therefore, further research is needed to clarify the level of distress in caregivers.

The results also support the second hypothesis that higher levels of social constraints from spouse on emotional expression would be related to higher levels of intrusive thoughts and general distress. These findings are consistent with previous findings examining how social constraint from significant other can heighten levels of intrusive thoughts and general distress among individuals undergoing various life stressors (Eton et al., 2005; Lepore et al 1996: Major
and Gramzow 1999). Eton et al (2005), for example, found that high social constraints from patients was associated with higher general and cancer-specific distress in spouses of prostate cancer patients. Lepore et al. (1996) found that grieving mothers experienced more intrusive thoughts 18 months after their infant’s death if they had not talk about their experience and feelings, which in turn heighten their distress.

The hypothesis that avoidance mediated the relationship between social constraints and intrusive thought is consistent with Schnur et al (2004) results that showed that the relationship between social constraints and intrusive thoughts, among women at elevated risk for breast cancer, was mediated by avoidance.

Avoidance did not mediate the relationship between general distress and social constraints. This is consistent with Cordova, Cunningham, Carlson and Andrykowski (2001) findings, as they did not find that avoidance mediated the relation between social constraints and depression in breast cancer survivors. However, these results are inconsistent with the findings from Schnur et al (2004) study which found that avoidance did mediate the relation between social constraints and general distress among women at risk for breast cancer. These descrepant findings could be due to various factors, such as different measures and subject population. For example, Schnur used Profile of Mood States–Short Version to measure general distress while the present study used Hospital Anxiety and Depression scale to assess general distress. The present study focused on spouses of prostate cancer patients while Schnur focused on women at risk for developing breast cancer.

It is possible that we failed to find that avoidance mediated the relationship between social constraints and general distress because the avoidance measure was specific to cancer or assessed avoidance of cancer related issues. Future studies should consider to examine if
avoidance of general negative feelings mediates the relationship between social constraints and general distress.

This study is not without its limitations. First, the sample size was rather small (n=42), in addition, we have no record of those who refused to participate. Therefore, we do not know if they are different from those who participated. Second, the participants were spouses of prostate cancer patients, thus the findings may not generalize to spouses whose partners have different type of cancer. Third, this was a cross sectional study which doesn't provide a good basis for establishing causality. Fourth, we used self-reported measures, which raises the issue of systematic positive or negative response tendencies. These limitations should be kept in mind when interpreting the findings. Despite these limitations the result of this study have number of important theoretical and psychological implications. For example, by determining the function of social constraints in foreseeing the level of intrusive thoughts in spouses of prostate cancer patients, the results could both deepen our understanding of intrusive thoughts in this population and imply that the social cognitive processing model can and ought to be engaged to guide psychological and research work in this area. Also, our findings that avoidance mediates the social constraints and intrusive thoughts not only adds to the limited body of work in this field but also provides an example of the powerful part of avoidance in predicting intrusive thoughts. Lastly, these findings proposes possible targets for psychological involvements in spouses of men with prostate cancer, and can be designed to decrease social constraints and avoidance.
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