The Impact of Social Constraints and Intrusive Thoughts on Distress among Newly Diagnosed Prostate Cancer Patients
Bryndís Dögg Steindórsdóttir

2013
BSc in Psychology

Author name: Bryndís Dögg Steindórsdóttir
Author ID number: 220986-2419

Department of Psychology
School of Business
Prostate cancer (PCA) is the most frequent cancer among men in the western world and causes many patients emotional distress. Increasing evidence suggests that distress around the time of diagnosis is one of the strongest predictors of subsequent distress, but little is known about modifiable factors that might contribute to distress around the time of PCA diagnosis. The aim of this study was to examine if the cognitive processing theory explained variability in distress among newly diagnosed patients. Based on that theory, it was hypothesized that intrusive thoughts about cancer would be associated with higher levels of distress but only among patients who perceived social constraints from their partner, on expressing their concern about the cancer. Participants consisted of 108 newly diagnosed PCA patients who completed a questionnaire measuring social constraints from spouse, intrusive thoughts and distress. Regression analysis revealed that there was a significant interaction between social constraints from spouse and intrusive thoughts on distress. The strongest relationship between intrusive thoughts and distress was when social constraints were high. These results indicate that when newly diagnosed PCA patients have the opportunity to express themselves to their partner, intrusive thoughts about the cancer have little impact on distress.

Útdráttur

Blöðruhálskrabbamein (BKK) er algengasta krabbamein á meðal karlmanna í hinum vestreina heimi og veldur mörgum sjúklingum tilfinningalegri streitu. Vaxandiissanar benda til þess að streita við upphaf greiningar sé einn sterkasti spáþáttur fyrir áframhaldandi streitu, en litið er vitað um þætti sem getu dregið úr streitu við upphaf greiningar á BKK krabbameini. Markmið þessarar rannsóknar var að skoða hvort að hugræna úrvinnslu kenningin útskýrði breytileikann í streitu á meðal nýgreindra sjúklinga. Á grunni þeirrar kenningar var sett fram sú tilgátu að ágengar hugsanir um krabbameinið myndu tengjast meiri streitu, en aðeins á meðal sjúklinga sem upplifðu félagslegar hömlur frá maka sínum fyrir því að tjá sig um krabbameinið. Þátttakendur samanstöðu af 108 nýgreindum BKK sjúklingum sem svöruðu spurningalista sem mat félagslegar hömlur frá maka, ágengar hugsanir og streitu. Aðhvarfsgreining síndi að það var marktæk samvirkni á milli félagslegra hamla frá maka og ágengra hugsana á streitu. Sterkasta sambandið á milli ágengra hugssana og streitu var þegar félagslegar hömlur voru miklar. Níðurstöðurnar benda til þess að þegar nýgreindir BKK sjúklingar hafi tækifari til þess að tjá sig um krabbameinið við maka, háf ágengar hugsanir um krabbameinið lítil áhrif á streitu.
Foreword and acknowledgements

“Submitted in partial fulfilment of the requirements of the BSc Psychology degree, Reykjavík University, this thesis is presented in the style of an article for submission to a peer-reviewed journal.”
Prostate cancer is the most frequent cancer among men in the western world and the second most common cause of cancer-related deaths among men worldwide (American Cancer Society, 2013; Krabbameinsskrá, 2013). Each year approximately 220 men are diagnosed in Iceland and around 50 die from the disease (Krabbameinsskrá, 2013). Even though prostate cancer can lead to death, almost 100% of men diagnosed can expect to live for at least five years and 93% for 15 years (American cancer Society, 2013).

Although survival rates are high, being diagnosed with cancer can be a major cause of stress and treatments for prostate cancer can have distressing side-effects such as problems with urine control, impotence and loss of sexual pleasure. Therefore, it is not surprising that emotional distress is common among prostate cancer patients (Balderson & Towell, 2003; Roth et al., 1998; Bloch, Love, Macvean, Duchesne, Couper & Kissane, 2007; Korfage, Essing Bot, Janssens, Scröder & de Koning, 2006). In a study by Balderson and Towell (2003), 38% of prostate cancer patients experienced distress. In addition, Roth et al. (1998) found that 15% of prostate cancer patients experienced depression and 33% experienced anxiety.

None of these studies assessed distress at the time of the diagnosis, but increasing evidence suggests that patients experience the highest level of distress when they are newly diagnosed (Carlsson et al., 2004; Kangas, Henry & Bryant, 2005; Korfage et al., 2006). For example, Kangas, Henry and Bryant (2005) examined distress in head, neck and lung cancer patients for one year. They found that distress was highest when the patients were newly diagnosed and declined during the first year after diagnosis. In addition, Carlson et al. (2004) found that newly diagnosed breast, prostate, colorectal and lung cancer patients reported more distress compared to patients receiving follow-up treatment.
It has been hypothesized that distress around the time of diagnosis is related to distress later in the cancer trajectory (Bloch et al., 2007; Korfage et al., 2006; Nordin, Berglund, Glimelius & Sjödén, 2001). Supporting this hypothesis, in a longitudinal study on mental health in prostate cancer patients, Korfage et al. (2006) found that anxiety and depression at the time of diagnosis predicted anxiety and depression 6 months later. Similarly, Nordin et al. (2001) found that levels of depression and anxiety at diagnosis were the best predictors of anxiety and depression 6 months later. As distress around the time of diagnosis has been found to be one of the strongest predictors of subsequent distress it is important to examine factors that might influence levels of distress in these patients in order to develop effective interventions early in the disease process.

The cognitive processing theory might provide a useful framework for understanding factors that might affect distress among newly diagnosed cancer patients. It has been well documented that the way in which individuals cognitively process their disease can have great impact on their adjustment to cancer (e.g. Lepore, 2001; Lepore & Helgeson, 1998). According to the cognitive processing theory, traumatic experiences, like cancer, can cause distress by challenging people’s core beliefs about themselves and the world (Janoff-Bulman, 1992). The cognitive processing theory states that in order to recover from trauma, individuals need to cognitively process their trauma-related information. When this process fails, the cancer-related information can remain active in the form of intrusive thoughts (e.g. flashbacks and dreams) (Lepore & Helgeson, 1998), which can in turn lead to distress and worse mental health (Devine, Parker, Fouladi & Cohen, 2003; Lepore & Helgeson, 1998). Devine et al. (2003) found, for example, that there was a strong and significant correlation between intrusive thoughts and distress.
One way to cognitively process cancer-related information is by expressing one’s emotions about the cancer. There are many ways to express emotions, e.g. by talking to supportive others or writing about one’s emotions. It has been well established that talking to others or writing about one’s emotions after trauma can have a beneficial effect on mental health (e.g. Pennebaker, 1997). This has also been demonstrated among cancer patients (Iwamitsu et al., 2003; Stanton et al., 2000). For example, Stanton et al. (2000) examined the impact of emotional expression on adjustment to breast cancer. They found that breast cancer patients who used emotional expression about their cancer as a coping method experienced decreased distress and improved physical health.

Following a traumatic experience, most people feel the need to express themselves (Kennedy-Moore and Watson, 2001). Therefore, they may require social support to meet these needs. Talking to supportive others may allow cancer patients to confront their intrusive thoughts about the cancer and integrate the cancer experience (Roberts, Lepore & Helgeson, 2006). Unfortunately, many prostate cancer patients experience constraints in expressing their emotions because they perceive that their social environment is not supportive enough (Lepore & Revenson, 2007). When patients perceive that other people respond negatively to their attempt to express themselves, they may suppress talking about their emotions and therefore have fewer opportunities to process their disease (Lepore, Silver, Wortman & Wayment, 1996). Studies among cancer patients have indicated that expressing emotions in a constrained environment can undermine cognitive processing and have an adverse effect on psychological well-being (Cordova et al., 2001; Devine et al., 2003; Lepore & Helgeson, 1998; Lepore & Revenson, 2007). The few studies available with prostate cancer patients have also found that social constraints are associated with
distress (Lepore & Helgeson, 1998; Zakowski, Ramati, Morton, Johnson and Flanigan, 2004).

One way in which emotional expression might have a beneficial effect on mental health is that expressing emotions about trauma-related information will lead to desensitization of intrusive thoughts about the trauma and distress (Lepore, 1997; Lepore et al., 1996). Consistent with this idea, Lepore et al. (1996) found that among bereaved mothers who had recently lost their children, intrusive thoughts were associated with more depression among women who experienced constraints in expressing themselves. Thus, women who felt they had sufficient social support for expressing themselves about the trauma were not as distressed by intrusive thoughts compared to women who experienced constraints in expressing themselves. Lepore and Helgeson (1998) examined this mechanism among prostate cancer patients and found that social constraints aggravated the negative association between intrusive thoughts about the cancer and distress. Men with prostate cancer who experienced difficulties expressing themselves with supportive others about their cancer were more likely to have intrusive thoughts and to avoid thinking about the cancer, compared with men who experienced no such difficulties. More importantly, those who experienced constraints in expressing themselves to significant others about their cancer were more distressed by intrusive thoughts about the cancer. They also found that social constraints from partners had more impact on patients’ distress than did social constraints from friends or family.

The above studies indicate that the cognitive processing model can explain how incomplete processing of cancer can lead to distress. However, all of these studies were conducted with cancer survivors long after the diagnosis and thus it is not known whether the cognitive processing model can also be applied to or explain
distress around the time of diagnosis. The aim of this research is to examine whether social constraints from spouse buffered the relationship between intrusive thoughts about the cancer and distress. Four hypotheses were put forward. First, social constraints will be associated with higher levels of distress; second, social constraints will be associated with higher levels of intrusive thoughts; third, intrusive thoughts will be associated with more distress; and forth, intrusive thoughts will be associated with higher levels of distress among those who report high levels of social constraints from their partner.

**Method**

**Participants**

Participants in this study were men newly diagnosed with prostate cancer. A total of 123 men were referred to the study and 15 declined to participate; therefore the final sample consisted of 108 men. All of the participants were recruited through contact with their treating physicians. To be eligible for this study participants had to be newly diagnosed with localized prostate cancer, have no previous history of cancer, and be able to read and write Icelandic.

**Procedure**

This study was a part of larger research project and was executed in collaboration with the National University Hospital of Iceland. The ethical committee in Iceland approved the study. Physicians treating patients for prostate cancer referred eligible participants to the study. Physicians explained the study briefly to their patients and asked if a member of a research team could contact them to explain the study further. If the patient agreed, the physician gave the members of the research team the patient’s name and phone number. The research team then contacted the patient within a few days, described the study’s procedure and objective and
scheduled an appointment for interested participants (see Appendix A). During the appointment, a member of the research team explained the study in detail, answered questions and obtained a signed consent form (See Appendix B). Subsequently, the questionnaire was administered. The participants answered the questionnaire in a private room and a member of the research team came in from time to time to check if the participant had any questions regarding the questionnaire.

Design

The design of this study was cross-sectional, as the questionnaire was administered once. To test the main hypothesis, two predictor variables (social constraints from spouse and intrusive thoughts) and one outcome variable (general distress) were used.

Measures

The participants completed a self-report assessment regarding basic demographic and medical questions, general distress, intrusive thoughts and social constraints from spouse (See appendix C).

Demographic and medical questionnaire

The participants answered both questions regarding demographic variables (e.g. age, educational level and employment status) and medical variables (e.g. time since diagnosis and type of treatment).

General distress

Distress was assessed with the Icelandic version of the Hospital Anxiety and Depression Scale (HADS) (Schaaber, Smari, and Oskarsson, 1990). The HADS scale is a 14 item self-report measure of anxiety and depression (Zigmond and Snaith, 1983). It contains two subscales, one that measures anxiety (7 items) and one that measures depression (7 items). Example items for anxiety include “I feel tense or
wound up” and “Worrying thoughts go through my mind”. Example items for depression include “I feel cheerful” and “I have lost interest in my appearance”. Participants were asked to rate how well each statement applied to them on a 4 point scale from “0: Not at all” to “3: Almost always”. A summary score for each subscale was computed and ranged from 0 (no distress) to 21 (maximum distress). The HADS scale has been found to be a reliable and a valid measure of anxiety and depression (Bjelland, Dahl, Haug & Neckelmann, 2002; Johnston, Pollard & Hennessey, 2000), with internal consistency ranging from .63 to .93 for anxiety and .67 to .90 for depression (Bjelland et al., 2002). In this study, the internal consistency was good for both of the subscales, or $\alpha = .83$ for the anxiety subscale and $\alpha = .82$ for the depression subscale.

**Intrusive thoughts**

The intrusion subscale of The Impact of Event Scale-Revised (IES-R) was used to assess the frequency of intrusive thoughts about the cancer (Weiss and Marmar, 1997). The IES-R scale was translated into Icelandic by Sjöfn Ágústsdóttir and translated back into English by Jakob Smári. The intrusion subscale includes 8 items (e.g. “Any reminder brought back feelings about it” and “Pictures about it popped into my head”). Participants were asked to answer how well each item applied to them on a five-point Likert scale ranging from “0: Not at all” to “4: Often”. A summary score was computed and ranged from 0-24, with higher scores indicating more intrusive thoughts. Previous research involving the intrusion subscale have found good internal consistency, ranging from $\alpha = .87$ (Weiss and Marmar, 1997) to $\alpha = .94$ (Creamer, Bell & Failla, 2003). The internal consistency of the intrusion subscale in this study was good, or $\alpha = .89$. 
Social constraints from spouse

To measure social constraints from spouse, the subscale of the Social Constraints Scale for cancer patients was administered (SCS) (Lepore, Silver, Worthman & Wayment, 1996; Lepore & Ituarte, 1999). The SCS scale was translated to Icelandic by Áslaug Kristinsdóttir and Jakob Smári translated it back to English. This is a 7-item scale measuring perceived inadequacy of social support from spouse that causes reluctance among individuals to express their emotions regarding their cancer experience. Participants were asked to rate how often they felt constrained in discussing their cancer to their spouse during the past 4 weeks (e.g. “How often did you feel that you could talk about your emotions regarding the cancer to your spouse when you wanted to?”) on a 4-point scale ranging from “1: never” to “4: always”. A summary score for this subscale was computed, with scores ranging from 7 (low constraints) to 28 (maximum constraints). Previous research with the SCS scale has found adequate internal consistency, with Cronbach’s alpha ranging from .71 to .81 (Lepore et al., 1996). The internal consistency for the SCS subscale, measuring social constraints from spouse was $\alpha = .71$ in this present study.

Data analysis

SPSS version 19 was used for analyzing the data. First, preliminary analysis was conducted to test whether any of the predictor or outcome variables were correlated with demographic or medical variables. Second, to examine whether social constraints from spouse buffered the relationship between intrusive thoughts and distress, linear regression analysis was conducted with the predictor variables intrusive thoughts and social constraints and the interaction between them on distress.
Results

Demographic characteristics

Participant’s age ranged from 45 years to 86 years, with a mean age around 66 years (SD= 8.7). Around half (53.7%) were employed and 37% were retired. Regarding educational background, 13% had only completed elementary school, around half had completed secondary school and 22% had completed a university degree. Participant’s mean time since diagnosis was three to four weeks (SD= 1.0). Around 23% had been diagnosed within two weeks before the measurement, 37% had been diagnosed between three and four weeks before, 31% between 1 and 2 months before and 9% 3 months before or longer. Regarding type of treatment, for half of the participants (52.5%), treatment had not been decided. Around 21% were going to have surgery, 13% watchful waiting, and 14% other types of treatment (radiotherapy, pharmaceuticals or hormone replacement).

Preliminary analysis

To determine whether any variables should be included as covariates in the analysis, the relationship between demographic and medical variables and predictor and outcome variables was examined. Age was significantly correlated with distress (r=-.241, p< .05) and with intrusive thoughts (r=-.270, p< .05). The younger the men were, the more distressed they were and the more frequent their intrusive thoughts were. Time since diagnosis was also significantly related to distress ($\chi^2(80, N=90) = 128.6, p< .05$), where patients experienced the most distress in the 3rd or 4th week after diagnosis. Including the variables age and time since diagnosis in the final analysis did not alter the results. Therefore, results are reported without these variables as covariates.
Descriptive statistics for predictor and outcome variable

Means and standard deviations for predictors and outcome variables are shown in Table 1. Although the average scores for intrusive thoughts were relatively low, there was high variability in the scores. Average scores for distress were relatively low but there was a wide variability in the measures, which suggests that some men experienced more distress than others.

Table 1

Means, standard deviations, possible and actual range of study variables (N = 101)

<table>
<thead>
<tr>
<th>Variables</th>
<th>M (SD)</th>
<th>Possible Range</th>
<th>Actual Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Predictor variables:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intrusive thoughts</td>
<td>5.32 (4.69)</td>
<td>0-32</td>
<td>0-24</td>
</tr>
<tr>
<td>Social constraints</td>
<td>9.80 (3.57)</td>
<td>7-28</td>
<td>7-21</td>
</tr>
<tr>
<td>Outcome variables:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distress</td>
<td>4.01 (4.52)</td>
<td>0-42</td>
<td>0-26</td>
</tr>
<tr>
<td>Depression</td>
<td>1.79 (2.42)</td>
<td>0-21</td>
<td>0-15</td>
</tr>
<tr>
<td>Anxiety</td>
<td>2.23 (2.57)</td>
<td>0-21</td>
<td>0-15</td>
</tr>
</tbody>
</table>

Note: Distress: Anxiety and depression.
As Table 2 shows, significant correlations were found between all study variables. There was a positive association between the predictor variables (social constraints and intrusive thoughts) and distress. There was also a positive relationship between the predictor variables, social constraints and intrusive thoughts.

Table 2

_Bivariate correlations for study predictor and outcome variables_

<table>
<thead>
<tr>
<th></th>
<th>Distress</th>
<th>Social constraints</th>
<th>Intrusive thoughts</th>
<th>Depression</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social constraints</td>
<td>.35**</td>
<td>-</td>
<td>.26*</td>
<td>.42**</td>
<td>.23*</td>
</tr>
<tr>
<td>Intrusive thoughts</td>
<td>.78**</td>
<td>.26*</td>
<td>-</td>
<td>.61**</td>
<td>.80**</td>
</tr>
<tr>
<td>Distress</td>
<td>-</td>
<td>.35**</td>
<td>.78**</td>
<td>.90**</td>
<td>.91**</td>
</tr>
<tr>
<td>Depression</td>
<td>.90**</td>
<td>.42**</td>
<td>.61**</td>
<td>-</td>
<td>.64**</td>
</tr>
<tr>
<td>Anxiety</td>
<td>.91**</td>
<td>.23*</td>
<td>.80**</td>
<td>.64**</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: *p<.05; **p<.001.

_Multivariate results_

Linear regression analysis was conducted to test whether social constraints buffered the relationship between intrusive thoughts and distress. As can be seen in Table 3, the result of the linear regression analysis shows that the interaction between social constraints and intrusive thoughts was a significant predictor of distress. The model accounted for 63% of the variation of distress ($F = 52.779, p<.001$).
Table 3

*Linear regression analysis for distress, with social constraints and intrusive thought as predictor variables*

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>B</th>
<th>St.err</th>
<th>β</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>1.441</td>
<td>1.199</td>
<td>(.941, 3.83)</td>
<td></td>
</tr>
<tr>
<td>Social constraints</td>
<td>-.81</td>
<td>.111</td>
<td>-.067</td>
<td>(-.302, .141)</td>
</tr>
<tr>
<td>Intrusive thoughts</td>
<td>.108</td>
<td>.173</td>
<td>.735</td>
<td>(-.236, .452)</td>
</tr>
<tr>
<td>Intrusive thoughts* social</td>
<td>.047**</td>
<td>.013</td>
<td>.113</td>
<td>(.021, .074)</td>
</tr>
</tbody>
</table>

Note: CI = confident interval. **p < .001.

To examine the effect of the interaction between intrusive thoughts and social constraints on distress in more detail, coefficients were calculated for intrusive thoughts at three different levels of social constraints (at 1 standard deviation above the mean, at the mean and 1 standard deviation below the mean). Figure 1 shows the effect on distress by the interaction between intrusive thoughts and social constraints. It shows how the effect of intrusive thoughts on distress changes with different levels of social constraints. The strongest association between intrusive thoughts and distress is when social constraints are high and the weakest association is when social constraints are low. Identical results were obtained when separate regression analyses were conducted for anxiety and depression.
Discussion

The overarching goal of the present study was to examine whether social constraints from spouse and intrusive thoughts would be associated with higher levels of distress in newly diagnosed prostate cancer patients and whether social constraints would buffer the impact of intrusive thoughts on distress.

As hypothesized, higher levels of intrusive thoughts and social constraints were associated with higher levels of distress. The findings that intrusive thoughts are associated with distress are in line with previous studies, which have found that intrusive thoughts are strongly associated with distress among cancer patients (Devine et al., 2003) and among prostate cancer patients (Lepore & Helgeson, 1998). The finding that social constraints were related to more distress is also consistent with previous research examining cancer patients (Cordova et al., 2001; Devine et al.,...
The findings also supported the main hypothesis that social constraints from spouse would buffer the effect of intrusive thoughts on distress. The results from the regression analysis revealed that there was a significant interaction between social constraints and intrusive thoughts on distress. The strongest relationship between intrusive thoughts and distress was seen when social constraints from spouse were high, and the weakest relationship was seen when constraints were low. When the interaction was examined separately for anxiety and depression, it was seen to be significant for both. These results indicate that when patients have the opportunity to express themselves to their spouse, intrusive thoughts about the cancer have little impact on their distress level. These results are consistent with Lepore and Helgeson’s study (1998), which found that prostate cancer patients, who experienced difficulties in expressing themselves to others, were more distressed by intrusive thoughts about the cancer compared to men who had no difficulties expressing themselves to others. In their study, social constraints from spouse had more impact on patient’s mental health than did social constraints from friends or family.

However, the studies above did not examine the impact of intrusive thoughts and social constraint among newly diagnosed patients. The present study demonstrates that social constraints from spouse and intrusive thoughts have an effect on distress among newly diagnosed patients. To our knowledge, this is the first study to show that social constraints from spouse can buffer the effect of intrusive thoughts on distress among newly diagnosed prostate cancer patients. This study also highlights the importance for newly diagnosed patients to have the opportunity to express themselves about their cancer to their spouse. Therefore, interventions aimed
at providing opportunities for patients to express themselves to their significant other might be beneficial and reduce distress among those who experience such constraints from their partner.

As distress around the time of diagnosis predicts distress later in the cancer trajectory, intervening early in the disease process could be beneficial in the long run. To date, we are not aware of any intervention studies that have examined interventions aimed at reducing social constraints from spouse and providing opportunities for patients to express themselves to their partner. However, interventions that provided prostate cancer patients the opportunity to express their emotions have been successful (Lepore & Helgeson, 1999; Lepore, Helgeson, Eton, & Schulz, 2003). For example, Lepore and Helgeson (1999) found that prostate cancer patients who participated in an intervention which included education and a discussion group were less distressed by intrusive thoughts, had more improvement in mental functioning and had fewer interpersonal problems compared to men in a control group. The results from the studies above indicate that interventions designed for patients to express themselves to others about their disease would be beneficial for their adjustment to cancer.

The findings of this study indicate that the cognitive processing theory can explain how incomplete processing of the cancer can lead to distress among newly diagnosed patients. According to that theory, in order to adjust to cancer, individuals need to cognitively process their disease (Lepore, 2001). When this process fails, the cancer-related information can remain active in the form of intrusive thoughts (e.g. flashbacks and dreams) and can lead to distress (Devine et al., 2003; Lepore & Helgeson, 1998). Expressing emotions after experiencing trauma has been found to be an effective way to process the trauma-related information (Lepore, 1997; Lepore et
al., 1996). The results of the present study support the desensitization mechanism, which states that expressing emotions about trauma-related information will lead to desensitization of intrusive thoughts about the trauma and distress (Lepore, 1997). In this study, those patients who experienced low social constraints and had therefore cognitively processed their cancer experience by expressing themselves to their significant other were less distressed by their intrusive thoughts. This is consistent with prior studies, both among bereaved mothers (Lepore et al., 1996) and among prostate cancer patients (Lepore & Helgeson, 1998) which indicate that when individuals’ social environment allows them to express their emotions after trauma, they can cognitively process their disease, which make them less distressed by their intrusive thoughts.

The findings of this study should be interpreted with caution because of its several limitations. Firstly, this was a cross-sectional study and therefore it is not possible to determine causation. For example, it is not possible to determine whether intrusive thoughts leaded to higher levels of distress or whether distress resulted in higher levels of intrusive thoughts. Secondly, self-report measures were used and therefore self-report bias might have influenced the results. Thirdly, we don’t have information about those participants who refused to participate. These participants might have something in common and we don’t know if they are any way different than other participants in the study.

Despite these limitations, these findings indicate that being able to express emotions to your significant other is an important predictor of mental health following diagnosis of prostate cancer. They suggest that there is a need to develop interventions early in the disease process, aimed at providing patients the opportunity to express
their emotions to their significant other, as such interventions might enhance their adjustment to cancer and be beneficial in the long run.

In the future, longitudinal and experimental studies are needed to demonstrate the causality between social constraints, intrusive thoughts and distress.

References


Creamer, M., Bell, R., & Failla, S. (2003). Psychometric properties of the impact of
event scale—revised. *Behaviour research and therapy*, 41(12), 1489-1496.


Appendix A

Guidance for introducing the research when calling the participants

Góðan daginn. Get ég fengið að tala við __________________________? Sæll, ég heiti __________ og ég fékk nafnið þitt frá lækninum þínum __________________________.

Ég hringi út af rannsókn á vegum Háskóla Íslands. Hvernig stendur á hjá þér?

Hefurðu nokkrar minútur? (Ef neitar: Hentar kannski að ég hringi í þig síðar? Skrá tíma)


Þátttaka felst í því að hitta okkur í eitt skipti í u.þ.b. klukkustund og svara spurningalistum um ýmislegt er varðar greininguna, heilsu þína og líðan. Þú myndir hitta okkur í Skógarhlíð 8 hjá Ráðgjafamiðstöd Krabbameinsfélagsins á 1. hæð, einu sinni. Siðan þyrfum við hringja í þig í þrigang heim til þín og tekur hvert skipti um hálftima. Þú þyrfir að hafa gott næði í þennan tíma. Í hvert af þessum þremur skiptum myndirðu svara örstuttum spurningalistum og skrifa í 20 minútur í einrúmi eftir ákveðnum fyrirmælum. Eftir þetta fengirðu senda spurningalista eftir 3 mónuði og aftur eftir 6 mónuði. Ëg vil taka það fram að allar upplýsingar í rannsókninni eru meðhöndlaðar samkvæmt ströngustu reglum um trúnað.
Er eithvað sem þú vilt spyrja um? Ertu til í að aðstoða okkur með því að taka þátt í rannsókninni?

-----------------------------------

Svarara játandi: Fínt. Þá þyrfti ég að bóka tíma þar sem þú munt hitta okkur í Skógarhlíðinni hjá Ráðgjafamiðstöð Krabbameinsfélagsins – þú þyrftir að gera ráð fyrir 1½ tíma en yfirleitt tekur bara um klukkustund að svara spurningalistunum? (Athuga að skoða lausa tíma í viðtalsherberginu hjá Ráðgjafamiðstöð Krabbameinsfélagsins)

Þakka þér fyrir og við sjáumst þá þá ______ daginn _______ (segja dags) kl. __________. Þú munt tala við __________________________ (segja nafn þess sem mun hitta). Það væri gott ef þú létir mig víta í síma _______ ef eithvað kemur uppá.

-----------------------------------

Nei: (Ef þáttakandi hefur ekki áhuga – útfylla skráningarform og/eða merkja við að hafi ekki áhuga)

Þakka þér fyrir og gangi þér vel í því sem er framundan hjá þér.
Appendix B

Informed consent and Introduction of the research

Kynning og upplýst samþykki fyrir þátttöku í vísin darannsókninni:

„Áhrif skriflegrar tjáningar á líðan karla sem greinst hafa með krabbamein í blöðruhálskirtli“

Rannsókn þessi er líður í doktorsverkefni Sigriðar Sjafnar Ágústsdóttur sálfræðings (sími: 898-3725, netfang: sigriag@hi.is) við Háskóla Íslands.

Það getur verið áfall og valdið miklu uppnámi að fá greiningu um krabbamein og það getur einnig verið erfitt að standa frammi fyrir því að þurfa að vega og meta ýmsa meðferðaskosti í kjölfar greiningar. Þess vegna er mikilvægt að komast að því hvaða aðferðir gefast best til að lina vanliðan og aðstoða þá sem nýlega hafa greinst með krabbamein í blöðruhálskirtli. Erlendar rannsóknir sýna að skrifleg tjáning er aðferð sem gefst vel til að vinna úr ýmissi áfallareynslu, hvort sem menn eru vanir að skrifa eða ekki og óháð því hvort þeir telja sig góða pennu eður ei. Rannsóknir sem byggjast á skriflegri tjáningu hafa ekki áður verið gerðar hérleðis og er því um að ræða fyrstu íslensku rannsóknina. Í ljósi erlendra rannsóknar teljum við að skrifleg tjáning geti hjálpað íslenskum körlum sem hafa greinst með krabbamein í blöðruhálskirtli.

Þátttakendur í þessari rannsókn eru karlmenn sem nýlega hafa fengið greiningu um krabbamein í blöðruhálskirtli. Við fengum nafn þitt frá lækninum þinum og þú samþykktir að við hefðum samband vegna rannsóknarinnar.
Pátttaka þin felst í eftirfarandi:

1. Að svara spurningalistum á þessum fundi í dag. Það tekur innan við klukkustund að svara spurningalistunum.

2. Að svara stuttum spurningalistum í þrigang (tekur um 5 minútur í hvert sinn) og skrifa í 20 minútur eftir ákveðnum fyrrirmælum í einrúmi heima hjá þér.

3. Að svara nokkrum spurningalistum í fjórgang og póstleggja þá, eftir um það bil 3 mánuði, eftir 6 mánuði, 12 mánuði og 24 mánuði. Það tekur innan við klukkustund að svara spurningalistunum í hvert sinn.

Þér ber engin skylda til þess að taka þátt í þessari rannsókn. Þú getur hætt þátttöku hvenær sem er eða neitað að svara ákveðnum spurningum án eftirmála og það hefur ekki áhrif á þá heilbrigðisþjónustu sem þú færð.


Þú gætir upplifað óþægilegar tilfinningar við það að skrifa. Ef þú upplifir mikla vanlóðan geturðu leitað til sálfræðisþjónustu Landspítalans í síma 543-9950 eða hringt í Sigriði Sjöfn Ágústdóttur sálfræðing og doktornsêma í síma 898-3725 og hún mun visa þér áfram.
Við metum mikils þátttöku þína í rannsókninni. Ekki er hægt að tryggja að þú hafir beinan hag af þátttöku, en erlendar rannsóknir benda til þess að skrifleg tjáning geti haft þákvæð áhrif á það sálraena og likamlega liðan í kjölfar greiningar og meðferðar krabbameins. Ekki verður greitt fyrir þátttöku í rannsókninni.


Ábyrgðarmaður rannsóknarinnar er Daniel Þór Ólason, prófessor við Sálfræðideild Háskóla Íslands, sími 525-5265, netfang: dto@hi.is.

Rannsóknin hefur hlotið leyfi Visindasiðanefndar og verið tilkynnt til Persónuverndar. Þetta bréf er í tvíriti og heldur þú eftir öðru eintakinu.

[Signature]

Sigríður Sjöfn Ágústsdóttir
Sálfræðingur og doktorsnemi

Daniel Þór Ólason
Ábyrgðarmaður og leiðbeinandi
Mér hefur verið kynntur tilgangur þessarar visindaranntsóknar og í hverju þátttaka min er fólgin. Ég er samþykktur þátttöku.

Dags. _____________ Undirskrift þátttakanda ____________________________

___ Merktu við ef þú hefur ekki áhuga á að taka þátt í rannsókninni

Nánari upplýsingar veitir Sigriður Sjöfn Ágústsdóttir s. 898 3725 eða sigriag@hi.is

Bestu þakkrir fyrir að gefa þér tíma til að kynna þér rannsókn okkar
Appendix C

The questionnaire

### Upplýsingar fyrir meðferð

<table>
<thead>
<tr>
<th>1 Dagssetning:</th>
<th>2 Aldur:</th>
</tr>
</thead>
<tbody>
<tr>
<td>DD-MM-ÅÅ</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2 Kennitala:</th>
<th>Ranmsakandi setur kenntölu þína og heimildsfang á gula skráningarblöðið með næfvi þínu og sína</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3 Hvar býðu?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4 Hverjar eru núverandi starfsaðstæður þínar?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>6</td>
</tr>
<tr>
<td>7</td>
</tr>
<tr>
<td>8</td>
</tr>
<tr>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5 Hvert er hæsta stig menntunar þínar?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>

________ % hlutfall
Greining og meðferð

Eftirfarandi spurningar eiga við um blöðruhlæskitilskrabbameinið og hvernig þad uppgötvadist.

8 Hvað er langt sérst þá fékkst fyrst vitneskju um að krabbamein hefði greinst í syni svona á blöðruhlæskití?

1. 0 til 1 víka
2. 1 til 2 víkur
3. 3 til 4 víkur
4. 1 til 2 mánuðir
5. 3 til 4 mánuðir
6. Meira en 4 mánuðir

14 Hvernig verdur brugðist við krabbameins greiningunní?
(vinsamlegast merktu við alla möguleika sem eiga við um þig)

0. Á ekki við, ekki hefur álveiði hvernig verdur brugðist við
1. Reglubundin eftirlit med gangi sjúkdómsins
2. Skorðaðgerð þar sem blöðruhlæskritillim verður fjárlægdur
3. Krabbameinslyðameðferð
4. Innri geslimameðferð
5. Ytri geslimameðferð
6. Hormónshvarfelameðferð
7. Óhefðbundnar leikningar, nánar tiltekið ______________________
8. Annað, nánar tiltekið ______________________
9. Veit ekki

Kviði og þunglyndi - HADS

Vinsamlegast merktu við þann svarreit sem á við hverja staðhæfingu.
Spurt er um líðan þína síðastliðna VIKU.

1 Ég er uppspenntur og tangatrekktur:

0. Áls ekki
1. Óðru hvorru, stundum
2. Of,
3. Næstum alltaf

2 Ég nýtt þess sem ég var vanur að gera:

0. Ábyggilega eins mikið
1. Ekki alveg eins mikið
2. Adeins að lítlu leyti
3. Varla nokktíð
3 Ëg fæ einhvers konar hræðslutilfinningu eins og eitt hvað hræðilegt sé að fara að gerast:
   0 ☐ Alls ekki
   1 ☐ Að little leyti, en Ëg hef ekki áhyggjur af því
   2 ☐ Já, en ekki svo sléma
   3 ☐ Alveg örugglega og oft sléma

4 Ëg get hlegið og séð það skoplega í kringum mig:
   0 ☐ Eins mikid og áður
   1 ☐ Ekki alveg eins mikid núna
   2 ☐ Ábyggilega ekki eins mikid núna
   3 ☐ Alls ekki

5 Áhyggjur fara í gegnum hugann:
   0 ☐ Aðeins stóku sinnum
   1 ☐ Óðru hvoru, en ekki svo oft
   2 ☐ Mjög oft
   3 ☐ Svo til stöðugt

6 Ëg er kátur:
   0 ☐ Svo til alltaf
   1 ☐ Stundum
   2 ☐ Ekki oft
   3 ☐ Alls ekki

7 Ëg get setið rólegur og slappað af:
   0 ☐ Alltaf
   1 ☐ Yfirleitt
   2 ☐ Ekki oft
   3 ☐ Alls ekki

8 Ëg er seinni til hugsana og verka:
   0 ☐ Alls ekki
   1 ☐ Stundum
   2 ☐ Mjög oft
   3 ☐ Næstum alltaf
9 Ýg finn til hræðoslukendum, fæ örøleikatilfinningu í magann:

0 ☐ Alls ekki
1 ☐ Öðru hvoru
2 ☐ Nokkuð oft
3 ☐ Mjög oft

10 Ýg hef misst áhugann á því hvernig ég lítið út:

0 ☐ Ég hirði jaðar vel um mig og áður
1 ☐ Kannski hirði ég ekki um mig eins og ég ætti að gera
2 ☐ Ég hirði ekki um mig eins og ég ætti að gera
3 ☐ Alveg örugglega

11 Ýg er örølegur, eins og ég þurfi allt af að vera að aðhafast eittvæð:

0 ☐ Alls ekki
1 ☐ Ekki svo mjög
2 ☐ Dó nokkuð miklið
3 ☐ Mjög miklið

12 Ýg hlakka til þess sem framundan er:

0 ☐ Eins miklið og áður
1 ☐ Eittvæð minna en áður
2 ☐ Örugglega minna en áður
3 ☐ Eiginlega alls ekki

13 Ýg fæ skyndileg ofsahraeðsluköst:

0 ☐ Alls ekki
1 ☐ Ekki mjög oft
2 ☐ Nokkuð oft
3 ☐ Mjög oft

14 Ýg get notið góðrar bókar eða skemmtilegs efnis í útvarpi eða sjónvarpi:

0 ☐ Oft
1 ☐ Stundum
2 ☐ Ekki oft
3 ☐ Mjög sjaldan
Áhrif streitvauðandi atburða - IES

Eftirfarandi er listi yfir umsagnir fólks um streituvaldandi atburði.
Skóða vör og sett atriði og merktu við hve oft þessar umsagnir hafa átt við þig
hvad varðar blöðurhálsktillskrabbamein síðan þú greinist.

1. Allt sem minnti mig á það kom tilfinningunum aftur af stað.
   0 □ Aldrei  1 □ Sjaldan  2 □ Stundur  3 □ Oft  4 □ Mjögg oft

2. Ég átti erfitt með að soفا.
   0 □ Aldrei  1 □ Sjaldan  2 □ Stundur  3 □ Oft  4 □ Mjögg oft

3. Ætir hlutir komu mér til að hugga um það.
   0 □ Aldrei  1 □ Sjaldan  2 □ Stundur  3 □ Oft  4 □ Mjögg oft

6. Ég hugsaði um það þó það hafi ekki verið ætlunin.
   0 □ Aldrei  1 □ Sjaldan  2 □ Stundur  3 □ Oft  4 □ Mjögg oft

   0 □ Aldrei  1 □ Sjaldan  2 □ Stundur  3 □ Oft  4 □ Mjögg oft

14. Ég lét stundum eða leið eins og ég væri kominn aftur til þess tímna þegar það gerðist.
    0 □ Aldrei  1 □ Sjaldan  2 □ Stundur  3 □ Oft  4 □ Mjögg oft

    0 □ Aldrei  1 □ Sjaldan  2 □ Stundur  3 □ Oft  4 □ Mjögg oft

20. Mig dreymdi um það.
    0 □ Aldrei  1 □ Sjaldan  2 □ Stundur  3 □ Oft  4 □ Mjögg oft
<table>
<thead>
<tr>
<th>Item</th>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Hversu oft fannst þér þu þurfa að halda tilfinningum þínun um krabbameinið út af því að þeirra þess að mabella þínun fannst þær eyðilegar?</td>
<td>Aldrei, Sjaldan, Stundum, Allt af</td>
</tr>
<tr>
<td>2</td>
<td>Hversu oft fannst þér þu geta rætt tilfinningar þínar varðandi krabbameinið við mabella þín þegar þú vildir?</td>
<td>Aldrei, Sjaldan, Stundum, Allt af</td>
</tr>
<tr>
<td>3</td>
<td>Pegar þu talðir um krabbameinið, hversu oft gaf maki þína í skynd að hún/hann vildi ekki hæyrta um það?</td>
<td>Aldrei, Sjaldan, Stundum, Allt af</td>
</tr>
<tr>
<td>4</td>
<td>Hversu oft fannst þér maki þínn bregðast þér með því að sýna þér ekki eins mikla ást og umbyggja eins og þú hefur viljað?</td>
<td>Aldrei, Sjaldan, Stundum, Allt af</td>
</tr>
<tr>
<td>5</td>
<td>Hversu oft hefur maki þínn verkilaga farari í tangarnar á þér?</td>
<td>Aldrei, Sjaldan, Stundum, Allt af</td>
</tr>
<tr>
<td>6</td>
<td>Hversu oft skipti maki þínn um umráðaefni þegar þú reyndir að tala um krabbameinið?</td>
<td>Aldrei, Sjaldan, Stundum, Allt af</td>
</tr>
<tr>
<td>7</td>
<td>Hversu oft tagöi maki þínn þér að hafa ekki svo miklar áhyggjur af heilsunni?</td>
<td>Aldrei, Sjaldan, Stundum, Allt af</td>
</tr>
</tbody>
</table>